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RECASTING HIV/AIDS AS A DEVELOPMENT ISSUE: OF RIGHTS AND RESISTANCE

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SECTION III

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Technical Report Series

This Technical Report Series is part of the Hivos-India Regional Office's effort to participate actively in the debate and dialogue in India on issues of human development and emancipatory interests. This series consists of monographs, working papers and Hivos conference proceedings. The publications reflect policy concerns of Hivos regarding development issues in India and address the problems faced by the marginalised in developing countries, such as in the areas of humane governance, environment, gender, the politics of development, technology choices and economic activities.

Series Editor: Shobha Raghuram

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We wish to thank all the participants who travelled to the meeting on HIV/AIDS at Puri, Orissa and spent time deliberating on the issue of HIV/AIDS. In particular we would like to place on record our appreciation and respect for those who participated in the panel on personal testimonies. It was a difficult and poignant session and their courage in resistance led us to the title of this issue 'Recasting HIV/AIDS as a Development Issue: Of Rights and Resistance' The staff of Hivos joins us in thanking Frans Mom, Senior Policy Officer for HIV/AIDS, Hivos, The Netherlands and Peter van Rooyen, Director, AIDS Foundation, The Netherlands for joining us at this workshop and making valuable contributions.

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Shobha Raghuram
Rajendran Nathan

SECTION I

CHAPTER 1

INTRODUCTION

Ben Witjes and Frans Mom

1. OVERVIEW

This report presents the outcome of two workshops on HIV/AIDS. The bulk of this report is concerned with the issues that emerged during the workshop on "AIDS: Impact and Intervention - Orissa". The workshop was held at Puri, Orissa, on 2-3 August, 1994. Section I and II contain the papers that were presented during the Puri workshop, together with a summary of the discussions that took place during plenary session and in working groups.

Also included in Section I is an overview of basic issues related to HIV/AIDS. We have included it since there still are many misconceptions with regard to HIV/AIDS.

The second workshop, "HIV/AIDS, Development and the Media", took place in March 1996, in Bangalore. This workshop was a co-operative effort of Hivos and the Centre for Education and Documentation (CED-Bangalore). Section III contains a brief report of that meeting.

In India, Hivos organised its first conference on "AIDS: Impact and Intervention"[1] in 1992. At that time, we started from the realisation that India might soon account for the largest number of HIV infected persons in the world. We also observed that most actors in India regarded HIV/AIDS as a medical and public health problem, whereas for Hivos socio-political, economic and cultural dimensions were of equal importance.[2] Thus there was a clear need to start supporting initiatives in the country that approached HIV/AIDS from a development perspective. At that time very few NGOs were involved in issues related to HIV/AIDS. Among the exceptions were the Indian Health Organisation in Bombay and Positive People, Goa, founded by the late Dominic D'Souza. A few journalists and human rights activists also stood out in their defence of HIV+ people who were arrested, forced into isolation, or confronted with other forms of discrimination. The dominant approach to HIV/AIDS, however, was quite different.

The first case of AIDS in India was diagnosed in 1986 from Chennai. Initial government efforts

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[1] For the report see Rajendran Nathan, Joy D'Souza and Shobha Raghuram (ed.), Proceedings of the conference on Aids: Impact and Intervention. 9 - 10 January 1992, Technical Report Series I.1 (1992, 19942), Hivos Bangalore.

[2] A number of articles on 'HIV/AIDS as a Development Issue' have been collected and reprinted as Background Papers for the HIVOS/CED workshop on "HIV/AIDS, Development and Media" (available at CED-Bangalore).

(from 1987-1991) focused almost exclusively on conducting studies in high risk populations such as commercial sex workers and truckers and on screening for HIV for blood transfusion. The National AIDS Control Programme, e.g. as it functioned between 1987 and 1991 almost exclusively focused its efforts on surveillance, i.e., the screening of blood. Only with the creation of the National AIDS Control Organisation (NACO) in 1992, did the government programmes begin to shift their emphasis to awareness raising, the promotion of safer sex practices, and support for HIV+ people.

After its 1992 conference, the Hivos Regional Office started supporting two major HIV/AIDS programmes in India. The Positive People, Goa project focused on the rights of HIV+ people and on public awareness. The second partner, the South India AIDS Action Programme (SIAAP, Madras) focused on intervention strategies with vulnerable communities like sex workers and truckers. SIAAP sought to promote effective protection, foremost by promoting condom use. SIAAP soon began the work extensively with other groups in south India. Out of this emerged two regional networks of NGOs, one in Andhra Pradesh and one in Karnataka. These networks aim to promote safe sex practices, and work towards the empowerment of vulnerable groups with a stress on sex workers.

One of the recommendations of the 1992 Hivos workshop "AIDS: Impact and Intervention" was to have similar workshops at the regional level. The 1994 workshop in Puri followed-up to that recommendation. At face value the choice of Orissa may seem a bit odd. In 1994, when the workshop took place, the levels of registered HIV cases in Orissa were among the lowest in the country.

Hivos had several reasons why it decided nevertheless to organise its first regional workshop on HIV/AIDS in Orissa. First of all, in south India HIV/AIDS intervention work had already taken off. Organisations like SIAAP were fostering new networks. Several donor agencies were supporting interventions in one of the worst affected states, Tamil Nadu. Second, Hivos has always believed that it has to concentrate its policy efforts and its funding to ensure that its interventions are effective. Orissa happens to be one of the concentration states for Hivos, primarily because of the high levels of poverty and marginalisation, especially in tribal areas. Hivos believes that a broad selection of NGOs, activists, and government bodies should become involved in HIV/AIDS intervention programmes. Because Hivos supports a significant number of NGOs in the state, it is in a position to act as a catalyst. The last, and perhaps most important reason as to why, in 1994, we opted for Orissa is that we feared that the low official figures were not representative of the long-term threats the population of Orissa was - and is - facing. Abject poverty and low levels of health, as are prevalent in Orissa, make people more vulnerable to HIV/AIDS. Increasing migration is another factor that promotes the spread of

STDs, which in turn makes the poor more vulnerable to HIV. Lastly, in the absence of a cure for HIV/AIDS, prevention strategies need to be set into place well before the virus spreads. Otherwise the lengthy invisibility of HIV infection makes the condition easy to ignore and this may help the epidemic to spread unchecked.[3]

The Orissa workshop was designed to create maximum opportunities for interaction between Orissa-based voluntary organisations, experienced HIV/AIDS activists from outside the state, government officials, researchers, and representatives of funding agencies. A status report prepared by Dr. Mohanty and Dr. Panda of the Orissa Voluntary Health Association, and the interventions by the state AIDS officer, Dr. Bisoi, provided an overview of the HIV/AIDS situation in Orissa as per mid-1994.

Up to 30 May, 1994, there were reportedly 30 HIV+ people in Orissa, of whom two developed AIDS. By January 1997, the number of reported HIV+ cases stood at 205 of which two had developed into AIDS.[4] Still small numbers, but a tremendous growth in two-and-a-half years. Such figures only tell a small part of the truth since they are based on the prevalence of HIV in tested populations. As pointed out above up till 1991, the National AIDS Control Programme focused heavily on screening blood, trying to test as many people as possible. Since 1991, NACO has taken a more selective approach and tried to base its surveillance on selective HIV testing. Consequently the number of tests done annually in Orissa has gone down. Furthermore, not all people who fall ill with HIV/AIDS are recognised as such, especially in a region where the disease is new. Since AIDS related diseases like tuberculosis are already rampant, many people would present with these diseases. Also suspected AIDS cases are not always reported because of the attached social stigma. Thus, when interpreting the figures for Orissa allowance should be made for under-recognition and under-reporting.

In their presentation Dr. Mohanty and Dr. Panda pointed out that the population of Orissa is already beset by a host of communicable diseases. Also infant and maternal mortality in the state are above the average for India. A high degree of migration and bonded labour and a low literacy rate increase the vulnerability of the population. A situation highly conducive to the spread of HIV.

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[3] Thomas C. Quinn, Global burden of the HIV pandemic, *The Lancet*, vol. 348, July 13, 1996, pp. 99.

[4] NACO figures as published in: *Nexus*, March - April 1997

Apart from the brief status report prepared by the Orissa Voluntary Health Organisation, three papers were presented during the Orissa workshop. The first was on *Women - Reproductive Health, and HIV* by Shyamala Nataraj of SIAAP Madras. An edited version of this is reproduced in this volume in Chapter 3. The second paper was by Dr. Vijay Thakur (Interaid) on *HIV/AIDS Ethics, Human Rights and Community Responses in India;* it is included as Chapter 4. The third paper was presented by Peter van Rooyen of the AIDS Fund, the Netherlands. In his paper Peter shared his experiences as a counsellor, working with people living with HIV and with AIDS in the Netherlands. Chapter 5 provides a summary of his contribution. A number of HIV-positive people were present in the Orissa workshop and related their personal experiences. They prevented the conference from becoming a theoretical exercise by and for development professionals only. Their testimonies have been reproduced in Chapter 6. Chapter 7 contains the reports of the group discussions which took place on the second and third day of the workshop. The last chapter of this section contains the remarks made at the conclusion of the workshop by Dr. Shobha Raghuram of Hivos Regional Office.

The Orissa consultation provided a platform for learning from each other's experiences, for exchanging information on current trends regarding HIV/AIDS, and for networking between groups, policy makers and activists. It was a good opportunity for the groups and activists to share their experiences and come up with practical suggestions for future plans of action in making preventive strategies and overcoming barriers for effective intervention.

For many of the participants the workshop offered a first opportunity to raise, think through, and discuss a range of issues related to the AIDS pandemic. Thus the workshop provoked a lot of debate on the ethical implications of dealing with HIV/AIDS. Participants discussed issues like compulsory testing; confidentiality; the human rights perspective of HIV/AIDS; the position of sex workers; and the right to privacy vis-à-vis the media. For Hivos, such issues are at the heart of the matter.

2. Hivos AND HIV/AIDS

Hivos started its work on HIV/AIDS in 1989. At first, most of us thought of AIDS as a medical rather than as a development issue. We also thought that HIV affected people mainly in Europe and the US, and there too especially homosexual men and intravenous (injecting) drug users. Slowly we realised that this was a false conception. Over the years it has become clear that developing countries are paying the highest toll. According to figures released by the World Health Organisation the number of persons living with HIV/AIDS stood at 22.6 million men, women and children at the end of 1996. By the year 2000 it is expected to rise to 26 million, more than 90% of whom will be in developing countries (only 8% of the funds for

AIDS research and prevention are spent in the South!). Although HIV was introduced much later in Asia than in sub-Saharan Africa, the USA or Europe, 23% of all persons living with HIV/AIDS are now in Asia, more than five million people at the end of 1996. The HIV/AIDS epidemic is now spreading faster in Asia than anywhere else in the world. By the year 2000, India alone is expected to have five million HIV+ people.[5] In India the states of Maharashtra, Tamil Nadu, Manipur and Goa appear to be most affected. Karnataka, Kerala, Andhra Pradesh, Uttar Pradesh and Punjab also show higher than average rates of infection. Although due to paucity of accurate information it is difficult to make a definitive statement on the variation in HIV rates in the different states; it is nevertheless clear that all states have large numbers of HIV+ people.

Apart from the mere size of the present AIDS epidemic and its future threat, there are other reasons why development institutions like Hivos cannot ignore HIV/AIDS. In the developing world HIV/AIDS affects broad sections of the population, especially people who are in the productive age brackets (between 25 and 44 years). Apart from the human suffering, HIV/AIDS thus severely affects the economic development of these countries. It not only causes a gap in the labour force, but it also forces governments to devote a substantial part of their health expenditures to one single disease, often at the expense of other health related problems. Families without wage earners face enormous social and psychological problems. In sub-Saharan Africa whole villages consist of only of children and the aged.

Although HIV/AIDS affects all sections of the population, the poor and marginalised are disproportionately affected: there is a strong link between social injustice and increased vulnerability to HIV infection.[6] The poor and marginalised are more vulnerable because of poor health and nutrition; they have less access to information on HIV/AIDS prevention; less control over their own and others behaviours; and less means to cushion the impact of the illness on themselves and their families. HIV/AIDS also leads to social disruption. When parents die, families disintegrate, leaving children behind as orphans, often placing uneven burdens on women and the elderly. Women are - again - more severely affected than men. They have a higher risk of contracting HIV infection than men.. Currently there are three men infected for every two women. By the year 2000 there will be almost as many women who are infected as men.[7] Women also have to shoulder the burden of extra care if their spouses, children or relatives are affected, whereas they can not automatically count on the same level

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[5] Such figures represent 'plausible trends'. "The longer-term dimensions of the HIV/AIDS pandemic cannot be forecast with confidence" - T.E. Mertens and D. Low-Beer, HIV and AIDS: where is the epidemic going?, in: *Bulletin of the World Health Organisation*, 1996, 74(2), p. 127. For a discussion of the reliability of the Indian fugures, see Nexus, Dec 1996 - Feb 1997, pp. 1- 2.

[6] See Richard G. Parker, Empowerment, community mobilisation and social change in the face of HIV/AIDS, in: *AIDS 1996*, 10(suppl 3): S27-S31.

[7] T.E. Mertens and D. Low-Beer, o.c., p. 122.

of care if they themselves become ill. Due to a lack of education women often have less access to information and services than men. Lack of income forces many women into prostitution. The article by Shyamala Nataraj in this volume provides a more elaborate analysis of Women & HIV/AIDS.[8]

The link between social injustice and vulnerability to HIV infection has yet another dimension: those who have been infected or are perceived as belonging to 'high risk groups' have often become victims of human rights abuses. Members of so-called "high risk groups" like sex workers and homosexuals, and HIV+ people have been harassed, forcibly tested and arrested. They have been denied access to health care, sacked by employers, and forced to leave their homes. This correlation of HIV and high risk groups can be traced to the history of HIV/AIDS. In the West it was detected in the homosexual community and seen as a "gay disease," and in India, as a disease of female commercial sex workers and truck drivers, and more recently, as disease of intravenous drug users. This focus on "high risk groups" has led to extensive, unsystematic testing among these groups, identification of HIV rates and a further increase in stigma and discrimination especially of sex workers who are perceived as spreading infection to the larger society. This concentration on "high risk groups" has also detracted attention from the fact that HIV is transmitted by high risk behaviours, which are by no means limited to certain group. Many of these groups are quite amorphous and do not have definite boundaries. This has also led to a feeling of complacency among the general population and has impeded the development of prevention programmes.

Hivos has called for specific attention for issues related to the pandemic of HIV/AIDS as a threat to development and as a human rights issue. Hivos's support to organisations concerned with HIV/AIDS focuses on three broad areas:

- innovative prevention strategies and advocacy efforts aimed at a more active engagement of governments in prevention programmes, in improving the legal framework, in providing STD services, and reproductive health care;
- respect for the human rights of so-called high risk groups, of people living with HIV/AIDS, and the promotion of their self-organisation;
- support to emancipatory processes at the cross-roads of HIV/AIDS and sexuality.

Empowerment of women and the breaking down of taboos concerning sexuality are of strategic importance both for prevention strategies and from a human rights perspective. Sexuality is a most complex terrain where relations of affection, desire and pleasure are intertwined with relations of power and domination. The HIV/AIDS pandemic has forced both

[8] Also see the Hivos policy document *Gender, Women and Development*, The Hague 1996.

women and men to become more open about issues of sexuality. Increasing women's bargaining power through strategies aimed at women's empowerment is important, e.g., women's right to inherit property has emerged as a critical issue for women whose husbands have died of AIDS. Efforts to assist women sex workers in increasing their capacity to negotiate safe sex practices are another example.[9]

Apart from women, migrants, prisoners, and homosexuals are other vulnerable groups. Until recently it was believed that heterosexual intercourse was virtually the only channel of transmission of HIV in developing countries (this in contrast to the developed world where the homosexual community is severally affected by the virus). Recent research, however, points out that a considerable number of men who consider themselves as heterosexuals also have, mostly unprotected sex with other men and that, this is another way the virus spreads. In a society with strict sex segregation, heterosexual men may not find partners, and resort to sex with men. For instance, in south India the wife returns to her mother's home for delivery and post-partum care. In such circumstances it may be acceptable for men to have sex with other women or men. In India, marriage is the norm for both men and women, so even men who are homosexual by orientation or preference may be married. Moreover, there is a growing recognition that some men (and women) in developing countries consider themselves as homosexuals. Rates of infection appear to be very high in this community, but due to a repressive climate these men are difficult to reach and therefore require well-adapted forms of intervention.

As a humanistic, secular development organisation, Hivos feels a particular responsibility with reference to the earlier mentioned taboos on sexuality.[10] Moral values regarding sexuality and gender relations are often perpetuated through religion and related dogmatic opinions and attitudes. By rejecting 'immoral practices' outright, the prevention of HIV/AIDS is often seriously hampered, e.g., impeding the distribution of condoms. The secular and undogmatic character of Hivos and its network of counterparts offers an opportunity to promote the debate on sexuality, sexual preferences, sexual health, and safe sex practices.

Within this broad thrust, Hivos chooses to concentrate on organisations that work with the urban and rural poor, who have limited access to elementary facilities and therefore are vulnerable to HIV infection. Besides, Hivos wishes to extend support to groups that are both vulnerable and have become victims of discrimination, this includes sex workers, homosexuals and bisexuals, and intravenous drug users. Support to self-organisations of these groups is high on the list of priorities. Migrant and refugee communities deserve special attention.

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[9] Ibidem

[10] The next few paragraphs draw upon the Working Paper *Hivos and AIDS*, The Hague, 1992.

Since 1989, when Hivos for the first time extended supported to an HIV/AIDS programme in Mexico, we have worked with a steadily increasing number of partners. Now, in 1996, Hivos supports more than thirty organisations in various parts of the world for their HIV/AIDS related work. These include self-help groups of people living with HIV/AIDS, organisations that stand-up for the rights of sex workers and homosexuals, and organisations which lobby with governments, media, and the general public for improved public policies, for the protection of human rights, and for more openness on issues related to sexuality, STDs, and HIV/AIDS. A few examples illustrate the difficulties nascent groups involved in HIV/AIDS had to face.

In Mexico, when Hivos started supporting its first HIV/AIDS related programme in 1989, there were about twenty NGOs already dealing with HIV/AIDS. These NGOs faced an unco-operative government, and strong opposition by political parties and the church. It was almost impossible to develop good projects on prevention and care. During our first visit to Mexico, we were introduced to these groups. One of them asked us to visit them first, because, as they put it: "We work with innocent victims." We had to make it clear that Hivos does not make that kind of distinction. We work with people who have HIV/AIDS and there is no question labeling one group as 'guilty' and others as 'innocent'. Against this backdrop, Hivos and its partners in Mexico gave much attention to human rights issues: when people were infected by the virus, they lost their jobs, they were isolated by their social environment, There was great effort to get this published by the press and to fight back.

Another experience in Mexico relates to the irresponsible stiff medication that was provided to 'high risk groups'. A gay initiative in Mexico campaigned against this. They worked under great pressure. In 1993, three leading gay and AIDS activists were brutally murdered. The authorities did not disclose this. Till today an NGO is fighting this case. Hivos strongly supports these kinds of activities in an effort to humanise the position of people who struggle against HIV/AIDS.

Another example, where co-ordination really worked was in South Africa. Here work started around 1991, almost from scratch. One or two groups gathered together representatives of 60 organisations with loose links, and founded a kind of umbrella organisation. They have a bi-monthly meetings to exchange experiences and views on policies, prevention and care.

Hivos also supported an initiative of young sex workers, male and female, who worked in the slums of Lima (Peru). They mainly do prevention work, under very dangerous conditions. They are subject to police harassment, in some cases are jailed and even raped. Rather than

stimulating public awareness, authorities target HIV/AIDS activists, who become a target of repression.

Yet another initiative supported by Hivos is a self-help group in Zambia. This is an initiative taken by a journalist and his wife who were infected by the virus. They organised a small group of people, started a magazine, and worked to get access to the press, in an effort to counter prejudice in the media.

Pink Triangle is a self-help group in Malaysia, where society and government share many pre-judgments on sexuality. Around 1990, it was absolutely impossible to start any HIV/AIDS programme in Malaysia, the government having denied the problem and projected it as a western issue. Pink Triangle persisted and after five years of hard work succeeded in convincing the central and local governments to take over certain initiatives of Pink Triangle, and make it an integral part of their AIDS prevention and care programmes. An example of a successful advocacy role played by an NGO. In India, Positive People, Goa, founded by the late Dominic D'Souza, has played a similar role. There are also a growing number of regional platforms.

Hivos attaches great importance to using the capacity of HIV+ people and of people living with AIDS. Self-organisation of those affected becomes a crucial empowering tool. In this, Hivos does not restrict itself to providing support to organisations in the South. It is also involved in raising awareness in The Netherlands itself that HIV/AIDS is a development issue. This has led to alliances with like-minded groups. One of the results of this is that the Dutch AIDS Fund is providing regular financial support to Hivos for activities in developing countries which aim at strengthening the position of people living with HIV and AIDS. In August 1996, Hivos and the AIDS Fund entered into a formal four-year agreement. Hivos also is a member of AIDS Coordination Group, a platform of donor NGOs, the Red Cross, universities, and government officials. With regard to HIV/AIDS policies, Hivos is an active dialogue partner with the Dutch Ministry of Development Co-operation, the European Union in Brussels, and UNAIDS. In interacting with these institutions, Hivos strongly supports efforts to enhance NGO participation.

3. CONCLUDING OBSERVATIONS

In this concluding section, we will highlight a few crucial issues which will shape Hivos's agenda for future support to HIV/AIDS related programmes in India. Most of these issues have cropped up frequently in our regular interaction with organisations and individuals working on HIV/AIDS prevention in India, including during the Orissa workshop.

Our first observation pertains to the way certain seemingly value-free concepts have gained currency and coined strategies. Most intervention strategies target certain '(high) risk groups', especially sex workers, truck drivers, and men having sex with men. This, as is observed in the contribution of Shyamala Nataraj, easily leads to victimisation and stigmatisation of such groups. They literally become a target. They are seen as harbouring the virus which they spread to an 'innocent' general populace. As we have argued already, experience shows that such strategies are counter-productive. Instead of targeting 'risk groups' it seems more appropriate to start interventions using the concept of 'risk behaviour', stressing that risk behaviour is not restricted to clearly circumscribed groups, but quite often involves a cross-section of society. The effort then is to sensitise those who engage in risk behaviour (unprotected sex, intravenous drug use, and, in a way, even blood transfusions) and point to the responsibility all of us have for our own acts and for the way these affect others. While encouraging responsible behaviour, it is important to remember that not all people have the ability to respond. Inequality in sexual relationships, especially between a sex worker and a client, makes it difficult for her to enforce condom use. Programmes need to "target" those most able to change their own behaviour, rather than those whose behaviours are largely governed by others and by circumstances without providing the support and skills for adopting behavioural changes.

This is not to suggest that everyone is equally vulnerable and that there is no space for organising groups involved in or exposed to high risk behaviour. On the contrary, public information, education and communication campaigns have their own limitations. This leads to our second observation: strengthening organisations of poor and marginalised communities is crucial in the fight against HIV/AIDS. In developed countries, the HIV/AIDS scenario has witnessed a transition from a reliance on the interventions of external agents to an increasingly important role for self-help groups. Although the professional support of doctors, nurses, lawyers, counsellors, et cetara, is indispensable, the voluntary support from friends, family members and fellow 'positive people' has often been crucial. Many have voiced their doubts about whether a similar self-help movement is possible in a country like India. It is often suggested that HIV+ people cannot 'come out' as they will be faced with repression and ostracisation. Therefore, the argument goes, they can only organise themselves with the help and under the aegis of non-infected professionals, social workers and NGOs. The repressive sexual, moral and legal climate - viz. the Indian acts against "unnatural sexual acts" and soliciting are often cited to substantiate this position. Hivos recognises the gravity of the situation. But we have also noticed there are those who have gone against the current and have fought to increase the spaces for new forms of self-organisation. Bombay Dost, India's first magazine for homosexuals, stands out as an early example. The 1994 Conference on

'Emerging Gay Identities in South Asia: Implications for HIV/AIDS and Sexual Health' organised by Humsafar Trust and the NAZ Project, was another path-breaking initiative. Equally encouraging is that in July 1996, the National Commission for Women (NCW), decided to make "Women in Prostitution' one of its main focus areas. Hivos's partner, SIAAP, has been instrumental in convincing the NCW of the importance of this issue.[11]

Self-organisation should, however, not be restricted to people living with HIV and with AIDS. If poor and marginalised communities are more vulnerable to HIV infection, empowering these communities is of the utmost importance. As Richard Parker argued during the recent Vancouver World Conference on AIDS, intervention in HIV/AIDS has to move

> "beyond information, education and communication campaigns in order to... equip vulnerable communities more adequately with the tools necessary to address their own vulnerability... Without overcoming the consistent denial of their basic rights and dignity, homosexual and bisexual men, sex workers and injecting drug users will continue to suffer the effects of the epidemic, independent of the degree of behavioural change on the part of individuals within these groups. Without transforming the unequal relations of gender power that exist in virtually every society, women around the world will continue to be preferential targets of HIV infection and will be unable to negotiate and guarantee their own safety. Without redressing the social and economic injustice that exists within nations as well as between the developed and the developing world, the poor (both in the north and south) will continue to suffer the major impact of (the) epidemic..."[12]

In this respect the growing self-consciousness and, as a result of this the self-organisation of sex workers in cities like Madras and Calcutta, is encouraging. This in turn, already has resulted in a better bargaining position for the women involved, leading to higher levels of protected sex. But, this has not worked in Kamatipura, in Bombay, despite the initiation of intervention programmes earlier than in Calcutta and Madras. This highlights the need for developing situation-specific interventions rather than a uniform programme for all areas.

A third important issue that is currently subject of debate is whether HIV/AIDS related interventions should be the work of specialised agencies or of broad-based development organisations. In our view, there is a clear need for specialised agencies, but there are strong arguments to also involve other voluntary agencies and authentic self-help groups. HIV/AIDS is not an isolated disease and it touches on broader health issues such as STDs, reproductive

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[11] See National Commission for Women, Societal Violence on Women and Children in Prostitution,New Delhi 1996.

[12] Parker, o.c., s. 32 .

health care, sexuality, and human rights. Moreover, it will simply not be possible to cover a country like India with a network of organisations specialising in HIV/AIDS.

Lastly, the growth in numbers of people infected with the virus, is slowly translating itself into increasing numbers of people who fall ill. Someone infected with HIV, can remain healthy for years, depending on his or her general physical condition, the availability of health care, and, the availability of AIDS-inhibiting drugs. In developing countries considerable progress has been made with cocktails of drugs which appear to delay the actual onset of AIDS by several years, and seem to yield good results even in those with fairly advanced AIDS. Most of these drugs though have serious side effects which some people cannot tolerate. This was one of the highlight of the XIth World AIDS Conference, held in Vancouver in July 1996. Because these drugs are very expensive (about U.S .$15,000 a year), and their daily administration and monitoring is a rather complicated process, this threatens to widen the already existing gap in survival chances between HIV+ people in developed and in developing countries. Already the number of people dying of AIDS in USA is on the decline, and health care professionals are beginning to consider AIDS as a chronic disease. Only a strong lobby with governments and pharmaceutical companies can redress the situation. Otherwise, "Like malaria once, HIV/AIDS no longer brings fear of death to the rich countries in the West, its rampancy - and its victims- in the poorer parts of the world may be ignored."[13]

For India, the reality that more and more people will fall ill with HIV/AIDS, will force all actors to rethink their priorities. Of course, the need to work for prevention is as urgent as before. But, the pressure on curative facilities for treating opportunistic infections (and for administration of the new drugs in super-speciality hospitals) will increase at a rapid speed. This includes a need for improved counselling services for HIV+ people, their relatives and friends, to help them to cope (see the contribution by Peter van Rooyen in this volume). It also includes medical as well as care - home care, respite homes, hospices and organised support for those who fall ill and their families. This is more than a question of more hospital beds, doctors and nurses. It requires that facilities are made available to enable communities, families, friends, and HIV+ people themselves to look after people with AIDS for longer periods and thus delay the moment where an appeal has to be made for institutional care. Appropriate medical and other facilities will have to be made available. Advocacy efforts and inspiring examples will be needed to create a conducive social, legal and medical environment for this

[13] *The Economist*, May 10th, 1997, . 85.

QUILT

During the first day of the Orissa seminar Frans Mom presented a flag made in memory of Dominic D'Souza. Dominic was the founder of Positive People, Goa. He was the first HIV+ Indian who came out in the open and stood up for the rights of people living with HIV/AIDS. Dominic died in June 1992. The flag for Dominic was made by some of his Dutch friends. On a dark green cloth the makers have glued a scarf, a symbol by which Dominic's friends remember him.

The idea of making flags to commemorate those who have died of AIDS was born in the USA. The first memorial quilt was made in San Francisco in 1985: eight flags remembering victims of the AIDS epidemic were put together in a panel. Soon after that the *Names Project* was founded. The project achieved world-wide recognition within a very short time. The exhibition in Washington in 1992, showed more than 22.000 flags. More than 30 countries have used the experience of the *Names Project* to set up their own Names Projects.

The flags are made by friends and family members of the person who has died of AIDS. Eight flags are sewn together to make a quilt. These panels of flags, measuring ± 4 x 4 meters are exhibited nationally and internationally during different events. The aim of such exhibits is:

- to honour and remember all those who have died of AIDS;
- to help people go through the mourning process after a close one has died of AIDS;
- to illustrate the dimension of the world-wide effects of the AIDS epidemic;
- to provide visual material during information sessions on AIDS and for fund raising campaigns.

Dominic's flag was taken to the World AIDS Conference in Yokohama (August 1994) where it was part of an exhibition. Thereafter the flag was handed over to Dominic's friends at Positive People, Goa. Those wishing to make a flag for their own friends or relatives who have died of AIDS and need further information can contact Positive People in Goa:

Positive People,
Flat A/7, Falcon Apartments
Near Cine el Dorado
Panjim, Goa - 403 001

We hope this volume is a contribution, not only to the debate on HIV/AIDS, but also to specific action to improve the lives of those infected by the virus, and to more sustained efforts to prevent further infections.

May 1997

CHAPTER 2

HIV/AIDS - FROM A DEVELOPMENTAL PERSPECTIVE

Since nutritional and infectious diseases like diarrhoea, malaria and tuberculosis claim a heavy toll in India, till the late 1980s many people in India, including health experts did not consider HIV/AIDS to be an urgent or priority health issue. HIV/AIDS was placed on the Indian agenda by international donor agencies and concerned public interest institutions. Despite the high rate of HIV/AIDS in sub-Saharan Africa, AIDS was still viewed as a disease of the western developed world which mainly afflicted homosexuals and the sexually promiscuous. By the early 1990s, however, it was apparent that HIV/AIDS rates in the West were reaching a plateau but were rising steeply in the developing world, particularly in South-east and South Asia. Even in these developing countries it was associated with poverty, inequality and marginalisation. Although HIV/AIDS is transmitted by a virus, it is a behavioural disease in that certain behaviours put people at risk. By modifying these risky behaviours, theoretically, the spread of HIV can be checked. However, it is important to remember that these behaviours, in practice, are determined and influenced by socio-economic and political factors that are beyond individual control. Similarly, positive people in developing countries are exposed to infections because to begin with their health status is already poor, they do not have access to safe water and sanitation, nutritious food, preventive health care, and live a stressful life in overcrowded situations. As this disease will disproportionately affect the poor, the consequences of the disease - unemployment, ill-health, loss of production, family disruption will occur in sections of society least equipped to deal with them. This in turn will affect national development by lowering production while escalating the cost of medical care. Thus, just as HIV affects all body systems, the causes and repercussions of HIV are systemic and affects the whole social system.

This chapter will attempt to place HIV/AIDS epidemiology, prevention and care options in the development perspective.

1. HIV/AIDS EPIDEMIOLOGY, TRANSMISSION AND PREVALENCE

1.1. BASIC INFORMATION ON HIV/AIDS

The acronym AIDS stands for "Acquired Immuno Deficiency Syndrome." AIDS is acquired. It is not genetic. It depresses the immune system that protects people against infections and it is a collection of diseases and conditions. AIDS is caused by the Human Immuno-deficiency Virus (HIV). HIV attacks and destroys specific white blood cells, essential for defending the body against disease. In addition to HIV, several co-factors, including poor health and nutritional

status, high prevalence of sexually transmitted diseases, and poor access to health care services increase the chances of acquiring HIV infection. These same factors hasten the progression of the infection.

Although HIV infection is life long, it is easily preventable. The virus is finicky and is easily destroyed by heat and common substances like bleach and detergent. The concentration of HIV in blood is quite low, and the virus does not survive in dried blood. Hepatitis B virus, another blood borne virus with a similar route of transmission is much more virulent, survives in dried blood, and causes acute disease in a short time. Yet HIV is more feared than Hepatitis B.

HIV can be present in the body for 5-10 or more years without producing any outward signs of illness. It is usually detected through tests that identify anti-bodies to HIV; anti-bodies develop only 6-12 weeks after infection. A person testing positive is said to be "sero-positive." This person has HIV infection, but he or she does not have AIDS. In most people, over time white blood cells are destroyed. Then infected people become vulnerable to various common infections (and some cancers) that usually do not trouble individuals with healthy immune systems. These infections are much more severe, prolonged and resistant to common treatment than in persons with intact immune systems. For instance they may have diarrhoea and fever for long duration and these may not respond to drugs. Similarly, more serious drug-resistant tuberculosis occurs more commonly in persons with HIV/AIDS. Only at this stage is the person considered to have AIDS. Eventually people with AIDS succumb to some of these infections.

1.2 MODES OF TRANSMISSION

HIV is mainly transmitted through:

a) Unprotected sexual intercourse with infected person/persons;
b) Transfusion of infected blood or blood products;
c) Use of infected needles and instruments;
d) An infected mother to baby, during pregnancy or delivery or through breast milk.

This virus is principally found in human body fluids in quantities sufficient to cause infection. The three main fluids are blood, semen and vaginal fluids. Any act that can transfer infected blood, semen or vaginal fluids into the blood stream of another individual can cause infection. In India 75-80 % of HIV is transmitted predominantly through the heterosexual route.[1]

[1] National statistics on HIV/AIDS prevalence is obtained from official press releases from NACO.

Although transmission through the sexual route is not efficient, this is the primary route of transmission. This is an indirect indication of the quantum of sexual activity. In terms of risk, obviously, transfusion of infected blood is the most risky. About 7-8% of HIV infection is reportedly transmitted through blood transfusion. Unfortunately in India over 60% of blood is donated by professional donors, usually poor, marginal and often desperate people, who are at high risk of being infected with HIV. With increase in voluntary blood donation and mandatory testing of all blood and blood products the transmission of HIV through this route is diminishing. Sharing contaminated needles for intravenous drug use is a major mode of transmission of HIV in some of the North Eastern states, especially in Manipur but only accounts for 8% of overall transmission in India. With more and more women acquiring HIV infection the transmission of HIV from the mother to the child is increasing. Recently NACO announced that there are 126 cases of paediatric AIDS. There are 30-40% chances that the baby of a sero-positive woman will also have the infection.

Body fluids like saliva and tears contain minute amounts of HIV, and theoretically HIV may spread through this route. Practically, however, these fluids do not contain a high enough virus load to transmit HIV infection. There is no documentation of infection via these fluids. The Centres for Disease Control and Prevention, USA estimate that contact with gallons of saliva is necessary to transmit infection[2]. On the other hand, breast milk contains sufficient HIV to transmit infection. A recent study estimates that that there are 14% chances of a baby getting infected through this route.[3] However, the World Health Organisation (WHO) and the National AIDS Control Organisation (NACO)[4] recommend breast feeding as breast milk confers anti-bodies and immunity to the baby and promotes mother-child bonding.. Moreover, hygienic bottle feeding is not feasible for most people in developing countries. Bottle feeding in unhygienic conditions causes diarrhoea which kills more babies than HIV. The chances of the infection passing through the mother to the child increase if the mother sero-converts, i..e. acquires HIV infection when she is pregnant or breast-feeding.

Any infected sharp instrument that penetrates the skin can potentially transmit infection, whether it be sharing needles for injecting drugs or administering drugs and vaccine, or razors used by barbers. The chances of contamination increase when the rate of HIV is high in a population. Thus, as the rate of HIV infection (there is a culture of sharing needles and

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[2] See Centers of Disease Control and Prevention document xxx.

[3] Get reference from Ravindran xxx.

[4] The NACO guidelines are essentially based on WHO recommendations for developing countries. Some Indian experts contend that this is discriminatory and that all positive women should feed alternative milk to their babies, and that the government and NGOs should provide support for this. Others are of the opinion that 14% is a reasonable risk. Moreover, if the child is already HIV+ breast milk, will enhance the baby's immunity and provide the best possible nutrition. Present tests for HIV antibodies cannot differentiate between the maternal antibodies and the child's own antibodies, so HIV antibody tests are only valid for children over 2 years (xxx check with Anita). If a woman can afford to give sufficient, hygienic alternative milk this option should be considered.

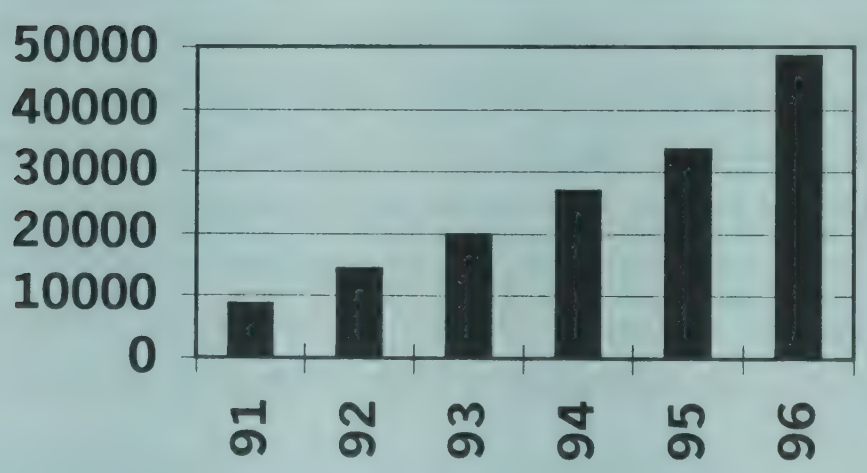
syringes among injection drug users (IDUs) in the North Eastern states, particularly Manipur,) is high, the risk of transmission is very high. The risk of infection through this route in the general population, in the absence of sterilisation, rises with the increase in rates of HIV.

Workshop participants sought clarifications on un-sterilised needles and razors. With regard to razors, there exists a general fear. For instance, in places like Tirupathi, where barbers are continuously engaged in shaving or tonsuring, there are chances of infection through the blood smeared instruments. However, world-wide record of such transmission is low or minimal as sufficient amount of virus to cause the infection should be present in the blood. HIV does not survive in dried blood.

1.3 PREVALENCE OF HIV/AIDS

Every day about 6000 people are getting infected with HIV/AIDS. AIDS is spreading faster in Asia than anywhere else in the world . It is time to take action. So far, it has been estimated that 4.5 million cases have occurred in adults and children (WHO/GPA).

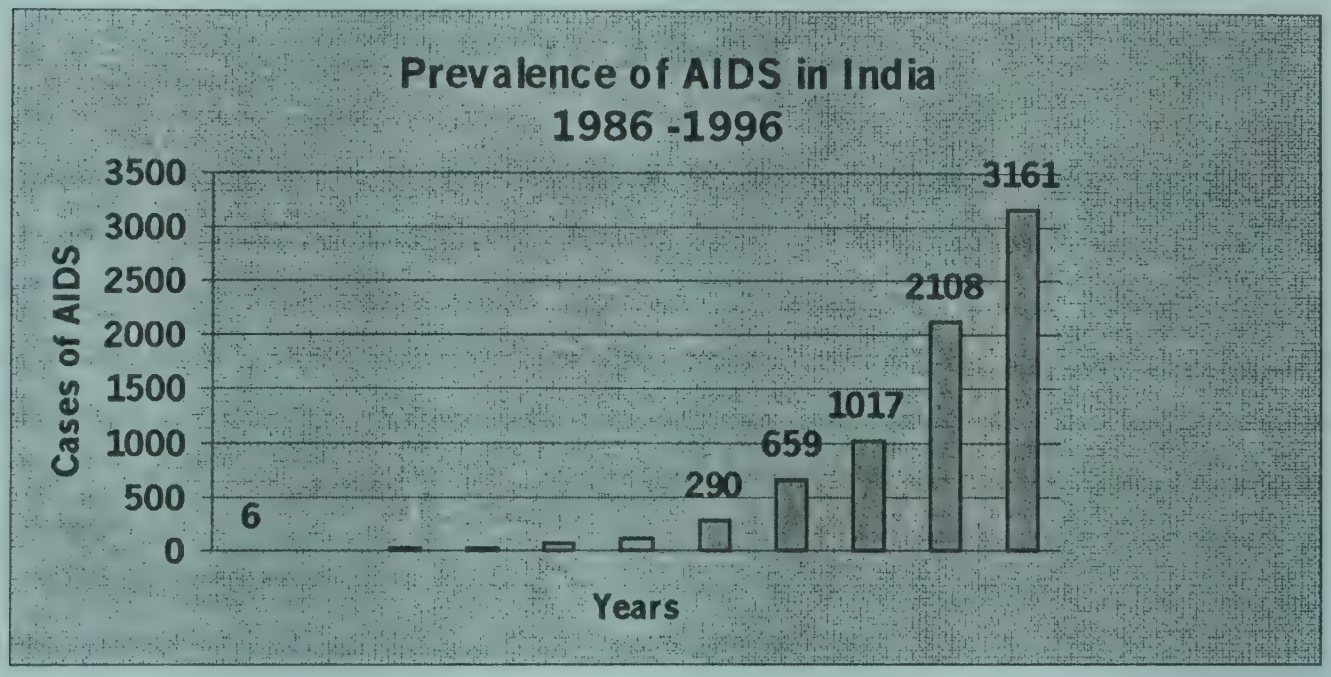
Prevalence of HIV in India



In India, HIV was first detected in October 1985 in a sex worker in Chennai, and in May 1987 the first AIDS case was identified in a blood transfusion recipient also in Chennai. During this initial stage of the epidemic, studies were not scientifically sound and were conducted in "high risk groups" such as sex workers and truck drivers. These figures could not be generalised to the population as a whole. Thus the exact number of people infected in India is unknown. Most experts believe that official reports vastly under-estimate the prevalence of HIV/AIDS The rate of HIV infection is highest among the 21-30 year age group. The highest incidence has been reported among the IV drug users in the North-eastern states and commercial sex workers in

Mumbai. Among the latter, 1.6% were HIV+ in 1988, 40% in 1992 and almost 70% in July 1996.[5], and two rounds of sentinel surveillance showed that 73.4% injection drug users in Imphal, Manipur were positive.

Among the 52,802 HIV+ people and 3386 people with AIDS in India (March 1997), over three-fourths had contracted HIV infection through heterosexual contact. The HIV sero-positivity rate was 17.8/1000.[6] Despite problems in obtaining an accurate epidemiological picture[7], it is evident that the rate of HIV infection in India is increasing in geometric proportion, doubling in less than a year.



Although the figures themselves may be suspect the trend in the rates of HIV infection and AIDS is alarming, and show a steady increase, a sharp curve with the rates doubling each year. In 1993 NACO started sentinel surveillance in "high risk" populations - STD clinic patients, injection drug users (IDUs), and a "normal" or "low risk" population- women attending ante-natal clinics. Data from these sources are collected from sites all over the country. Four rounds of data collected from STD clinics in Mumbai show an average prevalence of 26.4%, i.e. more than quarter of the patients have HIV infection. The shocking news is the increase in HIV prevalence in ante-natal clinics, a reflection of the presence of HIV in the "normal" population and not just in the high risk groups. HIV infection no longer remains confined to the so called high risk groups; it is rising in the general population. Results from two rounds of sentinel surveillance from Mumbai ante-natal

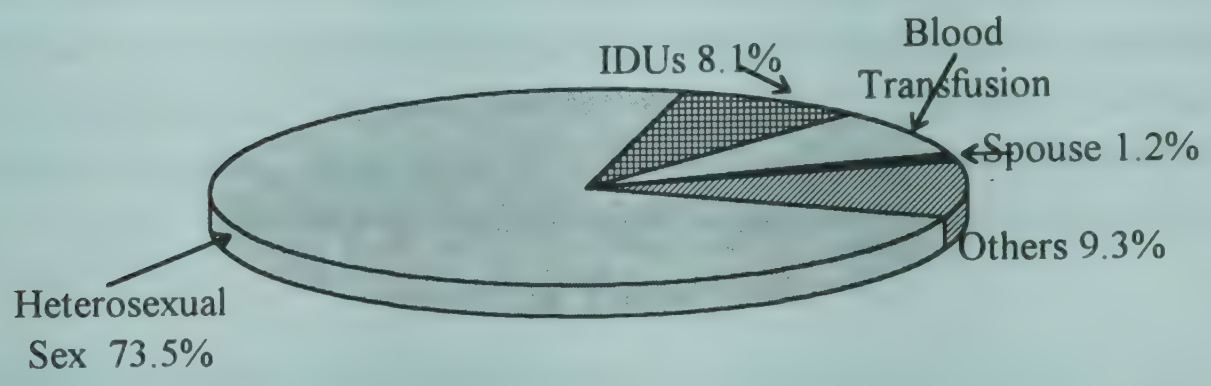
[5] As quoted in Sarman Singh, AIDS Care in India, *The AIDS Reader*, 7 (3) 101-106, 1997.

[6] National AIDS Control Organisation (NACO) Press release. From October 1985 NACO publishes cumulative national statistics periodically, usually quarterly. These figures may be revised at a later date.

[7] Mertens, T.E. and D. Low-Beer. (1996). HIV and AIDS: where is the epidemic going? *Bulletin of the World Health Organisation*, 74 (2) : 121-129.

clinics show a HIV prevalence of 2.38%.

Distribution of HIV+ in India by Mode of Infection



Apart from HIV, other sexually transmitted diseases (STDs) are a major public health problem. Among communicable diseases, after malaria and tuberculosis STDs are the most prevalent.[8] With an estimated annual incidence of 5 percent, approximately 40 million people contract STDs each year.[9] This is an indirect measure of sexual activity in the community in general, and points to "risky" sexual behaviour and multiple sex-partners. Majority of the patients who attend STD clinics are male, about a third are repeat visitors, and 12-25 % of them are in their teens.[10] The under-representation of women in STD clinics is at odds with the high rates of genital tract infections that have been detected in women[11], and is indicative of the culture of silence.[12] Here, more so than with other diseases, women either do not have access to health services or do not seek services.

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[8] Kapur, T. R. 1982. Patterns of sexually transmitted diseases in India, *Indian Journal of Dermatology, Venereology and Leprology*, 53.

[9] Pachauri, S. 1995. Defining a Reproductive Health Package for India: A Proposed Framework, *South and East Asian Regional Working Papers*, No. 4., Delhi : Population Council

[10] Ramasubban, R. 1995. "Patriarchy and the risks of HIV transmission," In Dasgupta, M., T. N. Krishnan and L. Chen (eds.), *Women, Health and Development in India*, Bombay, Oxford University Press.

[11] Bang, R. A. 1989. High prevalence of gynaecological problems in rural Indian women, *The Lancet*, 14 January 1989

[12] Dixon-Mueller, R. and J. Wasserheit. 1991 *The Culture of Silence: Reproductive Tract Infections Among Women in the Third World*, Washington, D. C., International Women's Health Coalition

STDs which cause genital ulcer disease or inflammation have been cited as a strong co-factor in the transmission of HIV. Among the 2800 patients attending a STD clinic in Pune between May 1993 to July 1994, 23.4% had HIV infection.[13] The rates of HIV among STD clinic population is steadily rising.

HIV Trends Among STD Clinic Attenders (in %) 1994 - June 1996

Cities	Round 1	Round 2	Round 3	Round 4
Mumbai	23	36	28.7	31.2
Nagpur	7	3	5.7	11.8
Madurai	6.4	6.5	8.3	9
Chennai	2.6	3.8	7	4.4

Early research and intervention[14] efforts focused on visible, marginalised "high risk" groups, such as prostitutes, intravenous drug users and truck drivers and the faceless majority received little attention. Increasingly as the common man, and more so, the common woman is getting affected, it is being recognised that women in stable unions, who are faithful, also have reasons to be fearful of contracting HIV and other STDs[15].

2. HIV/AIDS -IMPACT ON SOCIO-ECONOMIC DEVELOPMENT

It is increasingly recognised that the HIV/AIDS epidemic will seriously affect the socio-economic development of developing nations. The impact is evident in sub-Saharan Africa. It is also acknowledged that HIV/AIDS is perpetuated by poverty, inequality and under-development. The social and medical impact of this disease is the worst among under-privileged individuals, families and communities. AIDS is particularly devastating because it

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[13] Rodriguez, J. J., et al. 1995. Risk factors for HIV infection in people attending clinics for sexually transmitted diseases in India, *BMJ*, 311 : 283-286, 29 July 1995.

[14] Rao, A., M. Nag, M. Kingshuk, A. Dey. 1994. Sexual behaviour pattern of truck drivers and their helpers in relation to female sex workers, *Indian Journal of Social Work* 55(4):603-616.

[15] de Zoysa, I., M. D. Sweat, A. Denison, and J. A. Denison. 1996. A Faithful but fearful: reducing HIV transmission in stable relationships, *AIDS*, 10 (Supplement A):S197 - S203.

affects people in the prime of their lives.

In the countries which were affected early on in this epidemic, loss of human life in addition to the economic consequences has been enormous. Absenteeism is increasing as employees fall ill and this affects business adversely. Caring for the sick and loss of experienced and skilled workers in the formal and informal sectors leads to lower productivity, savings and investments. HIV/AIDS kills people who are at the most productive phase of their work life. This burdens the economy of the country. The economically vulnerable are greatly affected. For instance, workshop participants observed that some women were pushed into prostitution and manual workers into drugs. We need to plan for the management, care and rehabilitation facilities needed for the sero-positive people. In addition because so many of those infected are young parents, the community has to provide for the care of children and the elderly. The most important response is to strengthen the community to cope with this onslaught.

3. PREVENTION OF HIV INFECTION

Even though it is not possible to completely eliminate HIV, it is eminently preventable. HIV is acquired through various acts, by modifying these behaviours, theoretically it is possible to prevent all HIV transmission. In the beginning of the HIV/AIDS epidemic, certain groups such as homosexuals in the West, and commercial sex workers in India, were thought to be at high risk. This led to discrimination and victim blaming, and to a complacency in the wider society that this problem would not affect them. When HIV was detected in other sections of society people realised that it is behaviours, such as having unprotected sex, more than one mutually faithful partner, sharing contaminated needles and syringes and obtaining transfusion of untested blood that put people at risk and not membership of a certain group. This emphasis on behaviour allowed prevention activities to be focused on modifying these discrete behaviours. It is important to keep in mind that it is not so much the sexual behaviour of an individual but that of the "couple" that needs to be considered. When a person has sex with another he/she is virtually having sex with all that person's present and past partners and their partners and so on. If any one of them is infected with HIV there are chances that any one in this network can get HIV.

While focusing on behaviours it is important to keep in mind that behaviours occur in specific cultural, social, economic and political contexts. All people in any given society do not have the same power to control their own behaviour and the behaviour of others. For instance in India, married women who only have sexual relationship with their husband may still be at risk, because in many sub-cultures, it is not only acceptable but also expected that a man will have several partners. Similarly, many women and children and marginalised people like tribals and

those who have alternative sexual practices have little control over the behaviour of others that put them at risk.

During the workshop, several issues regarding migration and HIV infection were brought up. In several states, for economic reasons, there is mass migration of men or whole families to more prosperous rural areas or urban centres. Men living separately from their families for months at a stretch often have unprotected sexual relations with several partners thus increasing the risk of infecting themselves and subsequently, their wives. Men who travel regularly for long periods of time, like truck drivers and certain business men may also have multiple partners. Economic and sexual sub-ordinations also fuel the pandemic. The economic dependence of women makes them vulnerable.

It is not easy to change behaviours over time. We do not have a good understanding of sexuality or sexual behaviour. Sexual behaviour is varied, intricate and hidden, influenced by gender, social structure and culture. These behaviours encompass a spectrum from safe sexual behaviour to "safer", or risky/very risky sexual behaviours. In terms of transmission of HIV any form of unprotected penetrative sex is risky. Anal sex is particularly risky because the rectum is highly vascular (has a rich blood supply) and trauma is more common. In addition, condoms available in India are not designed for anal sex. Penetrative sex is more risky when the genital mucous membrane is broken. This is quite common among Indian women who cannot maintain good personal hygiene, who have untreated RTIs, STDs and other conditions related to multiple child births. In penetrative sex, the woman is at 8 to 10 times higher risk of contracting HIV from an infected man for several reasons:

a) the semen has a very high viral load;
b) the semen remains in the vagina for a time;
c) larger part of the genital tract is exposed to the virus;
d) undetected and untreated genital ulcerative diseases are common.

Abstinence is the safest option but not a realistic choice for many. A mutually faithful relationship would be safe. The emphasis here is not only on fidelity and faithfulness but on mutuality of this fidelity. Unless the partners are mutually faithful, the one faithful partner is still at the risk of HIV. In India, fidelity in women is valued and worshipped while men are not judged by the same standards. In fact, most women whose husbands have extra-marital relationships, simply say "men will be men." Next would be a wide range of sexual activities from fantasising or reading about sex to kissing, to sex with other parts of the body. Penetrative sex with proper condom use would be safer sex. The key here is a proper use of condom. In India the condom, is associated with contraception and it is not popular. The Family Health survey reports that only 2 percent of "eligible" couples use condoms. The rate is

somewhat higher among the educated. Condoms are also popularly associated with illicit sexual relationships. Moreover, most men feel that condoms inhibit sexual pleasure. This misconceptions need to be combatted.

Condom use is being propagated as a major strategy for preventing HIV/AIDS, and women are being "targeted" to promote condom use. It is becoming apparent that women hesitate to enforce condom use for various reasons: insistence on condoms in a stable relationship may be seen as lack of trust and as questioning of an intimate bond. Many women who are relatively powerless and are often faced with violence in sexual relationships cannot "make" their partner use condoms[16] are being burdened with the major responsibility of ensuring men use condoms.

3.1 TRANSMISSION OF HIV THROUGH THE SEXUAL ROUTE CAN BE PREVENTED THROUGH ADOPTING SAFE/SAFER SEX PRACTICES

a) Abstinence from sex (vaginal, oral/anal);

b) Mutually faithful sexual relationship;

c) Non-penetrative sex, e.g. hugging, cuddling, stroking, caressing, masturbation- self or mutual to sex with other body parts;

d) Unprotected penetrative sex (vaginal/anal) with one mutually faithful partner;

e) Protected (with condoms) penetrative sex with one or more partners (the risk increases with the number of partners). Regular and correct use of lubricated condoms for each sexual act is essential. Condoms should not be reused. Condoms should be stored in a cool place and should not be used if they are sticky or if the expiration date has elapsed. Oil or oil based lubricants- Vaseline, cold cream should not be used. Used condoms should be disposed off properly.

3.2 TRANSMISSION OF HIV THROUGH BLOOD TRANSFUSION (BLOOD PRODUCTS AND ORGAN TRANSPLANT) CAN BE PREVENTED BY

[16] For a discussion regarding women's risk, condom use and unequal sexual relationships see the following :Campbell, C. A., 1995. Male gender roles and sexuality: Implications for women's AIDS risk and prevention, *Social Science and Medicine*, 41(2):197-210.
George, A. 1996. Gender relations in urban households in Bombay: Challenges for HIV/STD prevention, Paper presented at the meeting on Reconceiving Sexuality: International Perspectives on Gender, Sexuality and Sexual Health, 14-17 April 1996, Rio de Janeiro, Brazil.
George, Anne 1994. Understanding sexuality: An ethnographic study of poor women in Bombay, India, Report in Brief, Women and AIDS Research Program, Washington, D. C.: International Center for Research on Women
Heise, L. L., and Elias, C. 1995. Transforming AIDS prevention to meet women's needs: a focus on developing countries, *Social Science and Medicine*, 40(7):931-943.
Heise, L., K. Moore, and N. Toubia. 1995. *Sexual Coercion and Reproductive Health: A Focus on Research*, New York, Population Council.

1. Ensuring that transfused blood has been tested for HIV;
2. Reducing the number of blood transfusions, single unit transfusions are unnecessary;
3. Using synthetic blood and blood component substitutes, transfusion medicine experts opine that there is no need for transfusion of whole blood in most circumstances;
4. Making autologous[17] transfusion facility available for elective or planned surgeries, in some hospitals in India even major surgeries like coronary by-pass surgery is being done with autologous transfusion;
5. Donating blood and ensuring a safe blood supply (so that blood banks do not have to rely on professional blood donors).

3.3 TRANSMISSION OF HIV THROUGH CONTAMINATED NEEDLES CAN BE PREVENTED BY

1. Reducing the number of injections- oral medication is safer, injections are for the most part unnecessary;
2. Ensuring reusable glass needles and syringes are sterilised properly. Steam sterilisation can be done in pressure cooker or by boiling for half an hour. This method may be the safest as it has been found that many "disposable" needles and syringes have been recycled. This method is also more ecological.
3. Proper use and disposal of disposable needles and syringes.
4. Health care workers adopting measures to protect themselves, e.g. wearing gloves while drawing blood.

3.4 TRANSMISSION OF HIV FROM INFECTED MOTHER TO CHILD: DURING PREGNANCY, CHILD BIRTH AND BREAST FEEDING

1. Primary prevention, i.e. preventing women from getting infected with HIV, especially during pregnancy and during lactation. If a woman sero-converts, i.e. gets HIV infection while she is pregnant or lactating, she has a high viral load and this increases the likelihood of the infection being passed on to the baby;
2. Identification of HIV+ women and counselling them about the chances of passing on the infection to the baby;
3. Regular condom use to prevent re-infection. Even women who are HIV+ need to protect themselves against re-infection with same or different strain of virus. Each exposure increases the viral load and heightens the chances of transmitting the

infection to the foetus;

4. Offering counselling and safe abortion facilities for HIV+ who want to terminate their pregnancy;
5. Offering HIV+ women who want to get pregnant or who are pregnant AZT prophylaxis treatment;
6. Treating the baby with Zidovudine (AZT) for the first three months after birth;
7. Providing hygienic and affordable substitutes for breast milk.

3.5 PREVENTION OF HIV TRANSMISSION THROUGH THE HEALTH CARE SETTING-FROM PATIENT TO PROVIDER, PROVIDER TO PATIENT OR PATIENT TO PATIENT

Following universal precautions,(it is assumed that any or all patients may be infected, hence, there is no need for HIV testing,) also offers protection against Hepatitis B and other blood borne viruses:

- Wash hands before and after caring for each patient;
- Use sterilised and disinfected instruments - boiling for 30 minutes is sufficient, 5 % bleach solution can be used for instruments which will not corrode, and for cleaning. Some commonly used disinfectants such as Dettol are not effective against HIV. Alcohol/surgical spirit is effective;
- Use gloves, masks and other protective clothing while carrying out invasive procedures.

3.6 TREATMENT AND PREVENTION OF DISABILITY

Once people are detected to be HIV+ they can take steps to maintain and improve their health by eating nutritious and hygienic food, drinking safe water, getting adequate rest and exercise, reducing stress and refraining from smoking and drinking alcohol. They could also protect themselves against infections and seek early treatment for ailments. Of recent remarkable progress has been made in the treatment of HIV infection. A combination of drugs that act on reducing virus replication, virus penetration of cells, and enhancement of immunity have for the first time succeeded in reducing the viral load and in increasing cells that provide immunity, even in individuals with low CD_4[18] counts.

[17] Collecting patient's blood prior to planned surgery, storing it properly using it during or after surgery

[18] CD_4 is a type of T helper white blood cell that is responsible for activating the immune system and it is especially targeted by HIV. The progression of HIV infection and the on-set of various opportunistic infections can be correlated to depletion of CD_4 cells, and treatment regimens are also based on CD_4 counts. Newer treatments are reported to not only halt the depletion of CD_4, but also support increase of these cells.

4. HIV TESTING

Testing is a misunderstood and controversial issue. Before dealing with the ethical and practical issues related to testing it is necessary to understand some basic facts. Commonly used testing methods identify anti-bodies to the virus, HIV. Usually a blood sample (new tests may use saliva) is tested. As mentioned before, antibodies to HIV develop only after 6-12 weeks after the infection. In this "window" period the test result may be negative even though the person is infected with HIV and can transmit the infection. During this period of sero-conversion the infected person usually experiences symptoms akin to influenza or viral fever, e.g. fever, body ache. At this time the viral load is high and the chances of transmission are greater.

ELIZA (enzyme linked immunosorbent assay) tests are very sensitive, i.e. they detect not only HIV infection but also other infections that may affect the immune system such as rheumatoid arthritis and malaria. For this reason, a single ELIZA test is not regarded as a definitive test. A sample that reads positive is re-tested twice using different kits. Only if the sample reads positive in all three tests is HIV infection confirmed. In case of ambiguous results, some laboratories also recheck these results with a fresh blood sample because contamination of the blood sample may also give a false positive result. Few years ago HIV ELIZA test results was confirmed by a Western Blot test that identifies HIV specific protein bands. The current NACO policy advocates testing by three different types of kits. The Western blot test is very much more expensive, needs training for interpretation, but does not yield a better result.

HIV antibody tests are not useful for detecting infection in infants younger than eighteen months because these children carry maternal anti-bodies. Tests that detect the virus or particular antigens can identify HIV infections in infants, but these tests are expensive and for the most part unavailable in India except for research purposes. Failure to thrive and repeated infections in infants of HIV+ mothers may be an indication of HIV infection.

A negative result shows the absence of anti-bodies to HIV, and may indicate no HIV infection at that point of time or infection in the window period. In case there is a strong suspicion of exposure to HIV, the test is repeated in 6 weeks time. In case of an equivocal result a positive test through one method and a negative by another a fresh sample is collected, and the tests redone.

Reputable laboratories take special care in following these procedures because of the psychological, social and economic implication of being falsely labelled as HIV+.

Unfortunately some laboratories issue positive results after carrying out only one test.

Apart from government surveillance centres, government and private laboratories, blood banks test for HIV. Blood banks use rapid spot tests which are very sensitive or ELIZA tests. The aim here is to ensure that the blood collected does not have anti-bodies to HIV. Any sample that tests positive is discarded.

4.1 HIV TESTING AND PREVENTION

Most people assume that HIV testing is closely linked to prevention of transmission. However, HIV testing is not necessary for adopting safer sex practices. HIV test should only be done with informed consent, that is only if the person understands what the test is about, how the test will be done, the implication of a positive test, and then voluntarily consents to the test. This voluntary informed consent lays the foundation for changes in behaviour that are necessary to maintain good health and to curtail transmission of infection.

A HIV test may be useful not only in prevention by interrupting transmission but also in helping to :

- Allay anxiety and uncertainty. Some people find it difficult to cope with uncertainty and a test result, either positive or negative is a relief. Others would much rather stay uncertain than know that they had HIV;
- Reduce risk of infection with another strain of HIV or a STD. A person infected with HIV benefits from adopting safer sex practices. This will reduce the chances of getting infected with the same or a different strain of HIV or a STD. Repeated infections of either HIV or STD will hasten progression to AIDS;
- Adopt health promotive measures such as better nutrition, maintaining good water, food and general hygiene, stopping smoking, reducing alcohol consumption and taking protective measures against common infectious diseases;
- Recognise and seek early treatment for common ailments, so that these do not become serious;
- Prevent spread of HIV infection

Considering that specific curative treatment for HIV is not available or is out of the reach of most Indians, testing is of no medical use, except that it might help a doctor to diagnose and better treat opportunistic infections. Thus, for testing to be useful it should be performed with informed consent, counselling and supportive care should be offered.

5. ROLE OF COUNSELLING IN HIV/AIDS

Counselling aims to enable a person to cope better with stress, find realistic ways to solve problems and make informed decisions. It is an important way to provide support to people who are HIV+. Preventive counselling or counselling for risk reduction can be done with or without testing for HIV. Pre- and post-test counselling is essential to prepare the individual to understand the implications of the test and to change his/her behaviour accordingly. People who are HIV+ and also those who are negative need pre-test counselling. Unfortunately few centres offer these services in India. (Another chapter specifically deals with issues of counselling and provides more illustrations. This section will briefly consider safer sex counselling, and pre- and post-test counselling.)

5.1 SAFER- SEX COUNSELLING

As an active educational programme, the truck drivers programme is a good example. Sex being a sensitive subject, the counsellor should first be comfortable discussing about sex/sexual practices and preferences. Sub-groups have their own vocabulary for the genitalia, sexual acts and practices. The counsellor needs to be familiar with these, Most importantly the counsellor should be non-judgemental.

Important steps in safer sex counselling are:

* Information on safer-sex - Alternatives to penetrative sex and methods of protection, especially correct condom usage should be discussed. The client should be at liberty to choose the method/s most suited to his/her needs. Correct condom use should be demonstrated;
* The difficulties and needs of adopting safer sex practices in their living situations should be discussed;
* The message be must be short and clear;
* Information should be presented in a non-threatening way;
* Counselling should be supplemented with educational materials like audio-visual aids and written materials that the client can refer to.

In our country little emphasis is laid on public education which is the main stay of prevention. Newspapers, magazines, radio and television are important media which should be utilised for this purpose.

5.2 CONFIDENTIALITY IN COUNSELLING

Confidentiality plays an important role in a counselling relationship. People are better able to

discuss their feelings when they know that the counsellor can be trusted not to betray their confidences. The counsellor has to keep in mind the rights of the clients as well as their spouses and partners. In the West, counsellor/client relationship is of primary importance and the spouse and family may not be involved closely. In the Indian situation, where the family unit is stronger, the counsellor, with the consent of the client, may take the spouse/partner into confidence.[19] The client, still however, decides what, when and how much to reveal to the partner or family. For instance, the positive person may not want to reveal his HIV status but only want his spouse to know that he has a disease or condition due to which he should not have children. He may tell his wife that he needs to use condoms because of this reason. This strategy may not work in the case of many couples as tubectomy is a common method of permanent contraception. In the Indian society people are under great pressure to marry. Infected single people may want to tell their parents that they cannot marry because of a medical problem.

The possible approaches are:

- Enabling people to assess the possibility of rejection by the loved one in a realistic manner;
- The counsellor can encourage them to look to other affected people, members of self-help groups and doctors in order to confide in them.

In counselling, behavioural changes and coping is facilitated by acknowledging and accepting emotions and by developing skills to handle them appropriately. The counsellor has to anticipate situations, such as rejection by loved ones and enable the client to assess the possibility in a realistic manner. Depression and suicidal thoughts occur quite frequently in those who are HIV+. The counsellor can encourage and assist positive people to link with other affected persons or self-help groups.

5.3 Pre-test counselling

The objective of this session(s) is to ensure that the person coming for counselling understands HIV testing and its implications, and is prepared for the test result. Only after completing pre-test counselling is the person's informed consent sought. This is the occasion to provide counselling on HIV risk reduction so that the person can take preventive steps before the results of the test are known. In addition, even if clients do not come for post-test counselling they can continue to protect themselves. The clients expectations and emotions are taken into cognisance. It is relevant that pre and post-test counselling should be done by the same person

[19] In the HIV/AIDS clinic at the National Institute of Mental Health and Neuro-Sciences, couple counselling has been found to be quite effective.

because they can keep the client's history, expectations, emotions in mind and, thus individualise the post-test counselling.

Illustration of the 17 year old pavement dwelling girl given elsewhere in this volume (ref. Personal Testimony) is a very lucid example of the emotions of HIV+ people. The situation becomes even more difficult when people are coercively tested for HIV/AIDS.

5.4 Post-test counselling

Post-test counselling is essential for both the HIV + and the HIV negative. The latter has to realise that because he or she is negative at this point in time it does not mean that they will continue to be negative if they continue risky practices. From the client's history of exposure, the counsellor suspects that the client may be in the window period, a re-test will have to be done in a few weeks.

Breaking the bad news is traumatic to the counsellor as well. The counsellor will have to gauge what and how much to disclose at the first post-test counselling session. While it is important to give factual and direct information to positive people, the initial session is not the best time to do so. Here it is imperative to consider and accept emotional reactions. Denial is a commonly observed initial reaction. Clients may request further testing. Anger may be directed at the counsellor or at the partner whom they suspect of "giving" them the infection. It may be followed by despair and deep depression. Positive people who do not have good social support get depressed and many may consider or actively try to commit suicide. The counsellor needs to assure clients that they are available in time of need. Frequent appointments should be scheduled during this early period. Practical arrangements must be made and, if need be, they must be referred to other institutions for assistance. Positive people need counselling at various points: when they encounter familial problems and problems in the work place and when they develop opportunistic infections and feel that the disease is progressing, when they get depressed or have a crisis.

PERSONAL TESTIMONY BY A HIV+ PERSON

Follow-up counselling and support for men and women with HIV/AIDS certainly requires strengthening. People with HIV have an important role in providing support to other infected people, as their experiences with the virus helps them to understand the feelings and reactions people like themselves. This is illustrated by the personal testimony by a positive person:

"I only have breakfast at home, I am not even served lunch. I am often in despair, without any support from anywhere and my life has been reduced to a sorry state. It is only through meeting people and sharing that I find some consolation. Knowing that there are a lot of people like me, I have started a "Self-support Group" with the help of my organisation. We contact HIV+ people and meet them every Sunday to provide some counselling and financial support. I wish to reach out to and to work with as many people as possible."

Other aspects such as case management, self-help groups and Training in HIV/AIDS Counselling have been dealt with extensively elsewhere in this volume).

6. WOMEN, REPRODUCTIVE HEALTH AND HIV/AIDS

Women are disproportionately affected by HIV/AIDS on several counts because :

1. They are more vulnerable to being infected with HIV transmitted through the sexual route;
2. They are more likely to receive blood transfusion. They have less power to negotiate safer sex practices;
3. They do not have access to safer sex method, which they can adopt without their partners being aware of it. They are dependent on men to use condoms. Female condoms are too expensive and their efficacy has not been well established;
4. They are the primary care givers in a family because they will have to care for their infected spouse, child and other family members;
5. With the increase in HIV infection in the community, younger and younger women i.e. girl children, who are thought to be safe do not have HIV, will be inducted into sex work or seduced.

Unless women's health, education, legal and economic prospects are improved, women will continue to be very vulnerable to HIV because they are not in a position to control their sexuality. Culturally women are socially led to believe that they have no voice in sexual matters, and that in marriage, sex is a man's right. They cannot make informed decisions not only because they do not have access to information but because they do not have the power to negotiate. Even in the context of marriage sexual intercourse takes place in a climate of violence and alcohol abuse, and marital rape is not uncommon.

Women, highly vulnerable to infection, are and will bear the brunt of the epidemic. Half of all the new HIV infections are in women aged between 15-24 years. As mentioned before, women are physiologically more vulnerable to HIV infection than men. Very young women are

particularly at risk because their genital tracts are immature and therefore there is more trauma during sexual intercourse. In addition, HIV progresses to AIDS faster in adolescents as their immune status is low. Death rates are highest among women in their 20's. Despite this high vulnerability of women, most people think of women as being a "reservoir" of infection. This perspective is reinforced by the media portrayal of women, especially sex workers as an epicentre from which HIV spreads. This view of women as conduits of sexually transmitting diseases is ingrained in society; the colloquial term for STDs in many south Indian languages is "women's disease." HIV too is being viewed in a similar light and women are not only blamed for spreading infection to men but also to children.

"Reproductive health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system, its functions and processes." The ICPD Programme of Action's endorsement of a reproductive health approach is a major success for women's health advocates.

6.1 HIV/AIDS AND STD'S AMONG WOMEN

In the 10th International Conference on AIDS, it was informed that an estimated 100 million cases of STD occur world-wide. Similarly in India it is estimated that 5% of sexually active people have had a STD. Of these, at least half of those affected are women. The role of STD, particularly STDs that cause genital ulcerative diseases, as a co-factor in HIV transmission is clear: They greatly increase the chances of contracting as well as transmitting HIV. Women face problems with STDs for several reasons:

- In women, several STDs, as well as other reproductive tract infections (RTIs), are asymptomatic, so women may not know they have a problem;
- Over 80% of infection in women remains untreated or inadequately due to variety of reasons:
  - Women think these problems are "natural", a part of women's life;
  - A "culture of silence" surrounds reproductive and sexual diseases and women shy away from seeking care;
  - Women do not have access to efficacious health care - either it is too expensive, too far away or services are provided at an inconvenient time. Often, especially in rural areas, there are no female doctors and women are reluctant to be examined by male doctors.
  - Even when they seek care they do not get appropriate treatment, and the attitude and behaviour of health care workers dissuades them from seeking care again
- Inadequate treatment with antibiotics leads to drug resistant organisms which cause

increasingly intractable infections. Self medication with antibiotics seems to be quite common in men. Studies among sex workers show that they routinely get injection of antibiotics for prophylaxis and treatment for STDs in general.

ILLUSTRATION

"HIV is spreading rapidly among women. If a man is infected with HIV/AIDS he does not reveal this information to his wife, but continues to have sex without using condoms. In this manner, more women are infected. Though her husband is the carrier of this infection, she continues caring for him, for herself and for her children. If her husband falls ill, she will need to work in order to support her family. Having to cope with these burdens when she herself is ill worsens her own condition and she is pushed towards death. There are many places where men can get themselves treated, but there are very few places where women can seek treatment when it relates to STDs. Therefore, women continue to remain silent about their infections."

The possible causes are:

* HIV/AIDS and STDs and their association with marginalised groups (sex workers) contribute to women getting blamed for the spread of HIV/AIDS.

Women have blood transfusions more often than men because of anaemia and complications of pregnancy and child birth. Here again, changes in health care practices can help to mitigate the situation. Although single unit transfusions are, on the most part, unnecessary, women routinely receive such transfusions. Thus the probability of women acquiring HIV infection due to blood transfusion is higher than that for men.

With men in the prime of life dying of AIDS, their sero-positive spouses or partners are under great pressure to generate an income (by any means) despite suffering from periodic bouts of illness.

Much of the care and support for people affected by HIV/AIDS falls on women's shoulders and a major task is to find ways of lessening the extra workload of women. Community support systems need to be developed to assist women and families. Women must have access to education, training and employment. They need to establish sexual relations on equal terms in order to control their risk of contracting HIV/AIDS. At all levels a gender based focus on

problems and solutions is urgently needed. HIV/AIDS patient care programme has to be designed in consideration of the needs of each community and women in particular.

The important strategies could be:

1. Control of STDs is imperative to slow down the HIV/AIDS pandemic;
2. It is important to destigmatise STDs and improve access to effective treatment. On method could be to integrate STD prevention and treatment into the reproductive health care package, which in turn needs to be incorporated with general health care.
3. It is also important to integrate sexually transmitted diseases control and AIDS control into social and welfare programmes at all levels.

7. HIV/AIDS AND HUMAN RIGHTS

Since the beginning when HIV/AIDS was detected in marginalised groups and associated with sexual behaviour, human rights and HIV/AIDS have been closely inter-linked. HIV/AIDS has reinforced stereotypes and discrimination. Stigmas associated with certain groups, gender and alternative sexual behaviours were transferred to the disease. Early on the in the epidemic the fatal nature of the disease was emphasised, conjuring up another taboo and a stigmatised subject - death. Even though HIV is not air, food or water borne, and has definite channels of transmission, that does not pose a risk to everyday casual contact, there were, and still are, some attempts to isolate HIV + people. Even health care professionals hesitate to come in contact with HIV + people, and deny them injections and other care. The issue of forcible testing has already been mentioned in the context of surveillance. This is also problem in accessing care. Many health institutions insist on a compulsory HIV test before performing surgery or other invasive procedures. HIV + people face discrimination in terms of employment, housing, access to health care, and some are shunned by their family and community.

ILLUSTRATION

In a government hospital, when a HIV/AIDS patient was in a serious state requiring IV fluids, the doctor and the nurse refused to administer it. Another patient from the same ward was asked to administer it. When asked the reason, the medical personnel replied that they dare not expose themselves to the risk as they had families to look after ! The same thing is happening in government based STD clinics and TB hospitals. The patients are put on oral medication instead of injections because of stigma.

The rights of anti-discrimination, workplace safety, privacy and confidentiality should be provided to the HIV/AIDS people. Focusing on human rights issues, discrimination experienced by HIV+ persons and their health care is extremely important.

8. ETHICAL AND LEGAL ISSUES IN HIV/AIDS

Ethical issues arise when there are differences of opinion. No two persons think alike. In medical practice, however, it is expected that certain moral principles are followed:

- Beneficence and non-maleficence: Good should be done and harm should be avoided;
- Respect for autonomy: Wishes and interests of the clients or patients should be respected;
- Justice: Wishes and interests of society and community at large should also be judged fairly.

Theoretically, if these principles are strictly followed, there should never be an ethical issue. However, quite often it is not possible to satisfy these three principles simultaneously, and this inevitably gives rise to ethical dilemmas. This is particularly the case when individual rights are at odds with community perceptions and interests.

The ethical issues in HIV/AIDS are:

a) Screening and testing policies;
b) Discrimination at the work place;
c) Blood safety and related issues;
d) Screening of pregnant women;
e) Access to and delivery of health care;
f) Bio-medical research, e.g. development of vaccine and drugs and trials;
g) Implementations of public health policies in prevention and control.

Focus on human rights and on discrimination experienced by HIV+ persons is particularly important.

With regard to law, participants thought that the Indian Constitution is broad based enough and no specific law is required to ensure protection except in terms of prostitution and homosexuality. Both are crimes in the eyes of law and this needs to be changed. The third area concerns the legality of providing safe injection paraphernalia to injection drug users.

9. SHORT-TERM AND LONG TERM PREVENTIVE STRATEGIES: GOVERNMENT AND NGO ROLE

Primary prevention is the first step. This would range from long-term strategy of general health promotion to short-term specific educational programmes to educate people about HIV/AIDS without inducing fear nor discrimination against those already infected. Sex education needs to be instituted and the concept and practice of safe sex needs to be promoted.

Short term immediate steps and strategies identified by the participants are:

1. To ensure that condoms are available free of cost, for a certain period of time;
2. To show and teach people the correct usage of the condom;
3. To empower women, especially sex workers, to adopt safer sex procedures by forming
4. self help groups;
5. To provide accessible and appropriate treatment for STDs;
6. To train field workers and community members to undertake HIV/AIDS prevention activities.

Other strategies could include:

1. Efforts to promote abstinence and delaying first sexual experience;
2. Ensuring safe blood supply by encouraging voluntary blood donation and testing blood;
3. Instituting "universal precautions" - to make health care settings safe for both providers and clients;
4. Providing counselling for positive people and their families;
5. Improving access and delivery of health care services to positive people;
6. Developing community support structures such as home-based care, respite homes and hospices to assist positive people and their families;
7. Advocacy to change policies and to ensure programmes are implemented;
8. Resource linking to access resources and to maximise on existing local resources.

Long term measures include efforts to improve the legal status of women, their income generating potential and their access to education. An equitable and just social structure which does not alienate or impinge on the rights of the poor or the minority will, in the long run, mitigate the spread of many infectious diseases including HIV/AIDS.

In this endeavour both NGOs and the government can and should play an active role. For instance NGOs can play a useful "watch dog" role in the issues of human rights violations. NGOs have already responded pro-actively to HIV/AIDS. They have delivered accessible and

effective services that cannot be matched by Government, inter-government and bilateral agencies bureaucracies. NGOs are invaluable partners in addressing the long term prevention and care needs of those affected by HIV/AIDS. Their work must be supported and encouraged by all, in particular by the National AIDS programmes. If NGOs have to start affirmative action programmes, their first commitment would be:

* To try their best to employ people with HIV/AIDS.
* To protect them from discriminatory actions such as loss of their jobs or homes or both.
* To protect the identity of HIV+ people (stop the media from revealing their identity)

ILLUSTRATION

In an unfortunate incident, the houses of women in prostitution were burnt and they were driven out of the village by the entire community due to the fear of the people that STDs and HIV/AIDS would spread faster through them. In the presence of a committed NGO, strong action could have been taken against this incidence.

The government initiated surveillance in 1985 and has set sentinel surveillance to gather more accurate pictures of disease trends. Obviously there are some things, like surveillance, which the government has the human resources and machinery to accomplish. The government has also initiated action to ensure blood safety, to create awareness and to train health staff. But still much remains to be done. The government has formulated policy to maintain confidentiality, pre and post-test counselling and for making government health services accessible to positive people. These policies have to be turned into action, programmes and services. Awareness and sensitisation programmes need to be directed at policy makers in various sectors, political and community leaders. NGOs can work with the government in these areas, support government action and ensure that laws and policies are translated into action. This needs coalition and lobby building. In the West, positive people have achieved much by working together to put their interests on the national agenda. NGOs can play a key role in organising and supporting such groups. As more and more people develop opportunistic infections they will need long-term care that hospitals and medical institutions are ill-equipped to provide. NGOs can take the lead organising home care, palliative care and establish respite homes and hospices.

10. SHAPING THE FUTURE: ALLIANCES AND NETWORKING

The HIV/AIDS pandemic can be addressed effectively only if rights and responsibilities are shared equally across the globe. Our country's scenario presents such a socio-economic situation that there is a need to work in co-ordination with the NGOs and the government agencies across the globe. It is equally important to involve people from various disciplines in participatory planning to make it more effective on a sustained basis.

Organisations like SIAAP and IHO have the main focus on HIV/AIDS and other organisations who are working on other developmental aspects can incorporate this issue and obtain technical support and guidance from them whenever they are needed.

During the discussions many of the participants expressed their wish that they would like to work with other groups. They also felt that they needed technical support, educational materials and other audio visual aids. There are many other international agencies interested in assisting and collaborating on a joint project for dissemination of technical and scientific information to developing countries. Networking is essential to ensure stronger position in achieving goals and targets, particularly in relation with effectiveness and demands towards policy matters. Networking at the regional level e.g. Asian People living with AIDS Network (APN plus), can address culture or region specific needs. The Global Network for People with AIDS (GNP plus) is working hard to link with the NGO sector.

HIV/AIDS presents an opportunity to focus on health and behaviours, rather than medicine. It gives an opportunity to examine and understand the complex, inter-related systemic factors that influence individual behaviour. It gives an opportunity to highlight prevention and education and demonstrate the shortcoming of narrow focus on curative medicine. HIV/AIDS presents and forces us to revamp our medical system - to rediscover the merits of asepsis and sterilisation the corner stone of good medicine for so long.. To develop safe blood banking system, to shift from unnecessary invasive procedures ranging from injections, surgery to blood transfusion. To move for "treatments and procedures" to care and underscore ethics, and patient rights. This strategy will result in the improvement in reproductive health of both men and women as well as enhance health in general.

It is up to the activist and those who have a public health orientation to seize this opportunity to bring about changes in gender relationships, to enhance women's control over their sexuality and sexual behaviour and to further human rights issues. The HIV/AIDS pandemic can be addressed effectively only if rights and responsibilities are shared equally across the globe.

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SECTION II

CHAPTER 3

WOMEN - REPRODUCTIVE HEALTH AND HIV

Shyamala Nataraj*

HIV is new but the problems that women face are not. The issue of the reproductive rights of women has assumed center stage in the dialogues on health among and within nations, regions and communities. Much heated debate has ensued within women's movements demanding equal or equitable rights. Currently, controversy is raging regarding trials of injectable contraceptives such as Norplant.

Paradoxically the basic issue, that of the reproductive health of women has received much less attention. Rhetoric seems to be winning over such fundamentals as diagnosis of problems, access to sensitive, confidential and affordable care, and meaningful communication between sexual partners. In effect, while women's groups are crying themselves hoarse over the issue of reproductive rights, the reproductive health of women continues to be un-addressed.

A well-documented and researched study conducted in Gadchioli district of Maharashtra showed that over a period of two years, 700 women were observed of which over 90% of the women suffered from gynecological conditions which included sexually transmitted diseases (STDs), pelvic inflammatory disease and cervicitis. Of this number 60% were sexually transmitted. The most common complaint was white discharge. When asked what they did about discharge, they said they did not do anything as it was natural for women to have white discharge. About 80% of them confessed that they did not talk to the doctor about it because they felt that it was the doctor's duty to ask them.

When asked about the importance of treatment and if they would take it when provided, 80% of them felt very strongly that treatment for white discharge is extremely important and they would be willing. Unfortunately there is very little documentation on the gynecological conditions of women or, for that matter, of men. We talk about malaria, diphtheria, infant mortality and all other health related problems, but where matters of sexual health are concerned, there is complete silence on the subject.

When I started working in this field four years ago in 1991, I travelled around Tamil Nadu looking for NGOs who had already worked on the issues of gynecological health and sexuality transmitted diseases. I also travelled around Karnataka and Andhra Pradesh looking for such NGOs. But, 99% of NGOs who had health programmes said they had no expertise and/or felt

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* This text has been reproduced from the transcripts of Ms. Shyamala Nataraj's talk at the Orissa Workshop - The Editor

it was difficult to provide reproductive health services in general and care for sexually transmitted diseases in particular.

Take the case of abortion services: These are legally available in the country and every year hundreds of thousands of women use them. However when performed in Government hospitals where it is free, an intrauterine device is compulsorily inserted in all women, and many women are unaware of its insertion. Even when they ask, they are unable to ask for details about its function. Of course no one bothers to educate women about its role, the precautions she may need to take, and the after effects she may experience etc. IUDs can cause skepticism, leading to other complications which can even be life threatening. At the least, it can cause heavy bleeding with stomach cramps and render really undernourished women anemic in a short while.

There is evidence that roughly 90% of all abortions are performed outside the government health centers under non-sterile conditions leading to infections. Most people helping with abortions are not trained to do so. A lot of women die because of abortion related infections. These infections could also lead to chronic gynecological conditions some of which will be conducive for increasing vulnerability to HIV/AIDS infection as well. This is because transmission of the HIV is facilitated by cuts/sores or open wounds in the vaginal area. Unprotected sex in these cases carry a high risk of infection.

At an STD/HIV workshop in Madras in June 1994, one of the participants, a medically trained doctor, point out that he had recorded reproduction related infection levels of nearly 60% strong women in his district. While figures may vary irregularly from place to place, it is evident that a large number of gynecological infections go untreated leading to genital trauma. It cannot be emphasised enough that such a condition is a particularly conducive condition for HIV transmission. Ironically STDs are easily treatable. Treatment costs are low, and prevention of re-infection is simple. The biggest hurdle is the unavailability of sensitive, confidential, accessible and effective treatment for women.

Despite such a high incidence, there is no attempt to mobilise awareness, motivate women to seek treatment and ensure that good quality services are provided. This is in sharp contrast to the attempts to deal with other health problems such as TB, malaria, cholera. Thus even as policy, the issue of reproductive health care among women continues to remains unaddressed.

PROTECTING THEMSELVES

Another issue is that most women do not even know which of their sexual partners may be

infected. How do they protect themselves and how do the men protect themselves? The present atmosphere of repression and oppression makes it very difficult for both men and women to communicate with each other about the issues of sex, health, infection and protection.

PREVENTING RE-INFECTION

The prevention of re-infection is absolutely important in all situations. In STDs particularly, re-infection after treatment can be prevented if condoms are used. Despite the array of contraceptives that are available to date, the condom continues to remain the only prevention for sexually transmitted disease. Yet the truth remains that women in this country and in many parts of the world are unable to ask their men to use condoms. So, even after post treatment recovery, there is a great likelihood of the women being re-infected if the man has unsafe behaviour. In such cases treatment becomes difficult and in time, people become more and more resistant to drugs for STDs.

It has been experienced that women around the world have a problem with enforcing condoms use. Surprisingly in Japan condoms are extensively used, though women in Japan are not more empowered than women elsewhere in the world. This has been due to the systematic promotion of the condom as a contraceptive as well as a prevention campaign against disease. Condom qualities are also very good.

WOMEN BLAMED

A major problem is the way in which women are blamed for their husband's sexual problems such as their infidelities. They hesitate to even approach this topic and prefer to ignore STDs since they are afraid that they will be blamed for this too. Very soon we may see a situation where they are blamed if their husbands are infected with HIV.

MARRIAGE AND WOMEN

The biggest challenge women face is the context of HIV in marriage. All of them are under strong compulsions to get married. But they are in no position to ascertain if the man they will marry has HIV or not. Besides, most often, men and women, are unaware of their HIV status though many of them, particularly men have/will have sex before marriage. Will they be protected? Will infection happen? Has it happened already ? How can women talk about this with each other ? How can they protect themselves and each other ?

This brings us to the issue of children. Women are under tremendous pressure to have children. But pregnancies and childbirth usually accelerate the onset of AIDS. What can a woman do under these circumstances? How does she decide and what are the consequences of these decisions? Perhaps there will never be one single answer. But we need to start asking these questions within ourselves and with each other so that all of us can feel more capable of dealing with HIV in our lives, individually and collectively.

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CHAPTER 4

HIV/AIDS-COMMUNITY RESPONSES, ETHICS AND HUMAN RIGHTS

Vijay Thakur *

I have the task of depicting two aspects of HIV related responses: 1) the ethical field created by the HIV pandemic with the application of contemporary human rights positions and 2) constructing a framework for an organised response for minimising and assimilating the epidemic. We need to search not only for what is desirable and appropriate but also for a dialect and a phenomenology. For these a beginning can be made from oneself and the evoked experiences and actions that HIV creates for the self. This could provide the counter-point to the hysteria that the epidemologic -centered reactions tend to create around HIV.

LANGUAGES FOR HIV: NEW LANGUAGES FOR POWER AND SEX

Someone has asked the question "What do you expect from us?" and before spelling institutional or individual roles and responsibility it may be worthwhile to examine the languages of "you-us,", "me and the other". Firstly, they arise out of grammatical necessity or perhaps they allow us to perceive the issues as out-there with oneself remaining excluded from the domain, in this case the HIV pandemic. Two, the language of "you" and "us" generates a-priori the practice of assistance, welfare and sometimes reform. The "you-us" assumes the self -appointment of a beneficent with the other as the beneficiary. Such a polarization actualises a moral situation under the face of a material one. The exclusion of moral imperatives, concealed or explicit is possibly the first step in evolving an appropriate and desirable response to the HIV-related situations. I have used the above example to depict the possible moralities vis-à-vis power.

A similar dynamic is visible in the term "commercial sex workers" that has been universalised by WHO, apparently to de-stigmatise prostitution. If the prefix "commercial" could be applied to any professional could we include terms like commercial health worker, commercial educationist etc. into our lexicon? Or is the phrase signalling a new beginning of the health regime for this group with its mandatory periodic check-ups, licensing etc.?.

Morality centered through sex is the other region where one needs to exercise caution and critique. Society through its history attempts to regulate and regiment human sexual behaviour and experience. Human sexuality is the focus of law, theology, religion and now science. We

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* This text has been reproduced from the transcripts of Vijay Thakur's talk at the Orissa Workshop - Editor

have to be cautious that our interventions, in the name of AIDS do not become tools for a modern moral regime for sexuality. The WHO for example has perpetrated the message of "single partner as safety from HIV infection" in all the developing countries.

Single partner imperatives have been with us since the birth of religion and therefore this ideology from an institution whose sole pre-occupation is "health" is confounding. Or is it an attempt to appropriate suitable ideologies from the domains of religion? The examination of our languages is perhaps the beginning for action with critique.

PERSPECTIVES FOR HIV/AIDS

You have possibly heard of these two perspectives: the medical (biological) perspective and HIV/AIDS as a health issue.

The method used within this attitude is of a modern health industry with the experience of the individual clinical condition as the centre of its gaze. All subsequent actions and perceptions are dependent on this clinical vision, whether it is epidemiology, therapeutics or education.

The second perspective postulates HIV/AIDS epidemic as a potential threat to the developmental effort and aspirations of a society. The epidemic is depicted in a sequence of phases, of increasing infections, illness and dying, socio-economic and cultural impact, survivors-children and the aging and finally the long term impact. Planning for effective action involves the recognition of possible consequences upon development, recording the evolution of the HIV related situation over time and developing flexible interventions that are responsive to the changing demands. These are the features of a response from this perspective. The responses are in synchrony with the phase of the epidemic and a plan for the predicted next phase. The responses are neither intrusive nor exterior to the community but given an initiative the response is organised by the community or representatives. The derivation of the method of community-based-response from the developmental perspective is the advantage over the "specialist" designed intervention.

A third possibility is of the human rights' perspective grounded in liberal and tolerant humanism. Unfortunately human rights is considered, at its worst, a jingoism or a bogey while at its best often remains a chart to adorn the office walls of NGOs. The problem with conventional "human rights" is its singular dependence on discourse and perhaps what is required is a kind of practical reason. As a method one could **articulate** statements of the rights, accessible and due, ratify a charter with the communities and assert through **consensus.**

A plan for the **actualisation** of the rights could then be worked out with the concerned constituency. For example: The right to work despite the results of an HIV antibody test could be actualised by working with trade unions, managers, industrial captains, legal systems and through direct contact with workers.

Finally the universal ethics of privacy, confidentiality, citizens' rights need to be constantly preserved and vigilance against violations of these is a feature of all desirable and effective initiatives and interventions.

LAW

There are two schools of thought. Some experts believe that the Indian Constitution is broad based and we do not require any specific law to ensure protection in this epidemic. The two exceptions to the above are laws concerning prostitution and the medieval act on men who have sex with men and women who have sex with women. The National Programme for HIV/AIDS prevention and control explicitly states ratification of these two areas of law as its objective before 1998. I think a third law regarding drug users, distinguishing "users" from pushers must be included in the present law along with protection for needle programmes and for prevention amongst injecting drug users. Fraudulent practices are also a major problem and the almost predictable pauperization of persons affected with HIV is one more unwanted consequence of this epidemic. It would be sufficient if somebody goes to the court. You are ensured of satisfactory response, because there are existing laws against fraudulent claims in medical practice. NGOs need to exert the instrument of law as a critical intervention and perceive that law impacts on all the other aspects of HIV related interventions.

WHAT HAS HAPPENED...?

To return to the history of the response in the HIV epidemic in India, the first as expected, has been denial: "Of course let us not talk about that, enough has been written about this."

The second phenomenon is an intense testing drive with the poor and women in prostitution being the first to be tested. Drug users, STDs clinic attendees, slum dwellers, people who have no voice, who come to hospitals seeking free treatment, have been classified into neat categories, tables and graphs. So this is the response of testing and segregating people.

The next response is this business of awareness which is actually propaganda. A traditional set of media instruments and publicists are deployed and posters, brochures, marathon runs, kite flying competitions, video clips, street and traditional theatre have been mobilised in many states in the name of AIDS awareness. Almost 30% of the budget of the national programme on AIDS/HIV is reserved for this activity.

In terms of the government and official response there has been one major achievement and that is the availability of condoms to NGOs. A village level NGO can be assured of a free and sustained supply of condoms, for HIV prevention and protection. This needs to be stepped up by listing the condom as a "life saving drug/equipment", thus ensuring high quality control over pricing.

The second minor gain is the availability of minimal health care and short term hospital care for persons who cannot afford treatments by those who have been refused treatment by private medical practitioners. Hopefully if government STDs services are improved, and will be able to offer treatment, counselling and condom programming points, the government response may become very valuable.

NGOs: More than 500 NGOs are today involved in AIDS related activities, which range from "celebrating" World AIDS Day(s) and campaigns of "information" with a few being involved in sustained community based initiatives.

The perception that there is an abundance of funds aids the inability to distinguish propaganda from awareness. The inability to conduct discourse within communities centered around sexuality, disease and dying are some of the handicaps that NGOs will find hard to overcome.

PLANNING FOR A RESPONSE: CONTROL OR CONCERN

At first let us recognise that the aims of "control" are dubious and often insidiously dangerous. It stems from the Victorian medical enterprise of hygiene and social order based on prescriptions of hygienic behaviour. It is unfortunate that our National Programme is titled an 'AIDS Control Programme.' Often within the pretense of social good and order is concealed the need to control and confine people and groups, especially those already oppressed and marginalised. If we look for an alternative, of a more authentic and effective response, how could we go about it ? The first step is to renounce the slogan 'control'.

DEVELOPING A RESPONSE

The first thing I would do is to question my concern. I would ask: "What is my concern about this epidemic, where does this concern come from?" There could be many sources of this concern. And if you are a group or if you are an institution, structure a discussion as to why your organisation wants to work with HIV. How and why is it that we are working with HIV?

PLANNING WITH THE COMMUNITY

The second step is to approach the community. I would begin by describing the problem: "there is a new sexually transmitted disease, which has started to spread. Here are the numbers, these are the reasons I feel concerned. I think this community will be affected. What do you think about it ? Is there anything we can do about it?". Thus we can begin a discourse with the community to present the problem as it is, and ask the community to plan a response, with desired outcomes and the action plans. This simple and effective strategy has been replaced by drawing board or donor driven programmes and methods. I hope we can now reverse this trend within HIV-related work and that would be a guarantee for effectivity. Planning for resources seems to be our natural first step like the proverbial cart before the horse. Thus often activities are made to "fit" into the budget.

EVALUATION

The strategy for continuous evaluation must be included into the plan and not done in an ad hoc manner.

AFFIRMATIVE ACTION

We should employ people living with HIV as workers, as managers, as people in our organisations. This should be a firm commitment of any NGO who is doing HIV related work.

PROTEST

Protest against discrimination that may happen to people living with HIV. Discrimination will include losing jobs, eviction from their homes, publicity in newspapers or denial of health care.

Use effectively public rallies and posters and kite-flying competitions, letters to the editors as awareness for protest. This may really help in minimising discrimination and civic rights

violations against persons and families affected by HIV.

CONCLUSION

We are a decade behind in developing effective responses. We will hopefully rise above the tons of posters, leaflets and training manuals and confront the communities with the realities and myths of this epidemic.

Many of the suggestions are well known. Many appear idealistic but these are imperative if we are to avoid evolving resistance and coping with HIV/AIDS into an expensive sham.

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CHAPTER 5

ROLE OF COUNSELLING IN HIV/AIDS

Peter Van Rooyen

Counselling is an interactive process: It is a question and answer game and is a talk between a counsellor and a client who needs counselling. Counselling aims at enabling a person to cope better with stress, find realistic ways to solve problems, and make informed decisions. It is very important that sufficient time is allotted for counselling. Regarding HIV/AIDS these are three types of counselling.

1. SAFE SEX COUNSELLING

It is a part of active educational programme such as the truck drivers' programme of SIAAP which reaches out to conduct safe sex counselling. In safe sex counselling the following steps should be taken into consideration:

a) Information on safe sex;
b) Safe use of condom;
c) Providing other need based information to overcome difficulties of people. This information must be short and clear without inducing fear. Visual and written materials must be made available to people.

2. PRE- AND POST-TEST COUNSELLING

All counselling must be conducted on a one-to-one basis under absolute confidentiality. It must be made clear that the test is not a tool for prevention and that, if the test is positive, there is no treatment.

In pre-test counselling people must be made to understand the exact implications of the test after ascertaining what the people have in mind. At the end of the pre-test counselling period, people must arrive at the stage of making an informed decision about the tests. At this stage, complete information on safe sex involving the usage of condom must be given. It is preferable for the same person to handle both pre and post-test counselling.

The factors to consider in post-test counselling are:

* It is important to give factual and direct information to the client;
* When the test result is positive, the client must be given the chance to express all his/her

reactions such as silence, sadness, anger and denial. The last mentioned is the most common of all reactions. At this phase, practical arrangements need to be made.

These pre and post-test counselling sessions form a good basis to take appropriate action to help the HIV+ people.

3. COUNSELLING FOR PEOPLE WITH HIV/AIDS

Different types of counselling are available for people with HIV/AIDS such as individual counselling, pre-test and post-test counselling, and counselling by professionals and self-help groups.

CASE MANAGEMENT

It is a central service to collect all the information required for people with HIV/AIDS. This service also assesses the present and future needs of these people and deals with practical situations of money, housing and work to arrive at a plan of action. Advocacy becomes a part of the counsellor's work. It is very important to maintain a data bank for HIV/AIDS people to help them to manage on their own and to refer them, if necessary, to other support referral services. Hence, there is a requirement to have a good overview of the nature and work of other NGOs and their activities in the surrounding environment.

SELF-HELP GROUPS

They are services through which people with HIV/AIDS support each other. This is achieved in various ways such as one to one sessions, regular groups and drop-in centres. They empower themselves by providing actual support to each other in such a way that it leads to advocacy. It is very hard to break down cultural barriers, and other fears. When all barriers are overcome, highly rewarding results are observed. In the absence of loved ones, self-help is essential.

DISCUSSION NOTES

Q. In India, for the past six years, training programmes comprising of two or five day workshops for medical personnel such as doctors, nurses and technicians are being conducted. But, are they sufficient for the nature of training required for a counsellor for HIV/AIDS related counselling?

depth counselling for HIV/AIDS cases. Our experience shows that HIV/AIDS counselling is a long-term continuous process.

Once the trainee-counsellors have acquired the basic skills such as communication and counselling, an enormous amount of groundwork is needed. There must be a two-way communication between the trainers and the trainees. Our trainers must also be facilitators and be able to cope with various situations in the field. This training process was started in Manipur last year. In the Northeast, five groups are intensively involved in this process. A lot is being learnt from the field activities. It is a fact that we learn more from working with HIV/AIDS people than from psychiatrists and psychologists.

In the Netherlands, when the initial services were started, they began as a Clinical Psychology Unit with a psychiatrist. Later, a need for social workers was felt as they were better than others in meeting the needs and demands of people with HIV/AIDS. HIV/AIDS counselling necessitates talking about sexual matters without being judgmental. Usually, people find it a difficult prospect.

ILLUSTRATION

An experience in counselling a pregnant woman:

A 17-year old pavement-dwelling girl is HIV+. She has severe resistant STD and is two months pregnant. After becoming aware of this fact, she refuses to meet anyone outside her group on the streets which indulges in glue sniffing and petty crimes. She does not discuss condom use and is afraid to terminate her pregnancy. She entertains six to seven clients everyday.

Through a query, it was ascertained that she was counselled before being tested. But, a situation arises where people are tested forcibly without proper knowledge or consent and when the test is positive, they cannot cope with the situation. Our workers get frustrated and exhausted while working with such cases.

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Professional counsellors find it a very rewarding experience to work with people with HIV/AIDS as they learn to give of their all as these are sick people who have lost their own loved people and "all" are facing the loss of their own lives.

Professional people and managers who have a vision of the future must support people with HIV/AIDS, encourage them to counsel other infected people in order to empower them and to have a positive effect on them.

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CHAPTER 6

COPING WITH HIV/AIDS

PERSONAL TESTIMONIES *

Testimony I

It is very difficult to openly admit, "I am HIV+" because of the stigma attached to it. I came to know about my condition on the 21st August, 1992, during a medical examination preparatory to proceeding to the Gulf on an assignment. I was terribly shocked at the news and reached home in the same shocked state with all my dreams shattered.

At that time I was not aware of HIV, but I knew vaguely that it had something to do with AIDS. Told my family about my condition, but I was fortunate that there was no change in their attitude towards me. They gave me courage and love which is what the HIV+ person requires. For about eight months, I was so desperate that I felt like committing suicide. I had a good job in a hotel, but I resigned.

Then I read an article in the newspapers about an NGO working for HIV/AIDS prevention and education. I approached them and then onwards my entire life changed. Today I work as a counsellor.

> "A little message to HIV+ friends. Have hope, we will not die. Soon a vaccine or cure will surely come"

TESTIMONY II

I wish to share with you how I acquired this HIV infection. I am a homosexual individual. When I was young, I never received any affection from my parents, who used to constantly abuse me. In order to find some peace, I used to go to the beach or the park, where I was picked up by other men and taken to their rooms. I was paid Rs. 50 for each such encounter. I continued this practice till my college days. It was my belief that HIV/AIDS is contracted only through women and not men! Even my other homo-sexual friends had the same notion. My life is a living example of the fact that HIV/AIDS can spread through homo-sexual men as well. I was offered a job when I left college and I was ready to get married. But, my previous high risk behaviour made me go in for a test. When the test was positive, I decided not to marry.

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* Confidentiality has been maintained and minor details altered - Editor.

I was frightened to share this result with my family. When my father noticed that I was distancing myself from them, he wanted to know the reason. When I disclosed the reason, I was asked to leave home. I went to live with my grandmother. My father would not speak to me. When my relatives heard about the result, they were all upset and I felt like committing suicide. Then, I met a person who said that I might be of help to the society and community in preventing the spread of this infection. This changed my mind and I joined an organisation. I knew that I would hurt my family when I decided to speak out. In fact, it did upset them very much when I gave interviews to Hindi newspaper and on T.V, and now, they do not speak to me.

I had heard a lot about counselling. But, there was no counselling at leading medical establishments in two cities which I visited. I state this emphatically because, when my cousin tested positive at one of these hospitals, his results were simply handed over and he was asked to leave without any counselling. Eventually, I had to travel to counsel him.

"However, after knowing that there are a lot of people like me, I have started a self-help group with the help of my organisation. We contact HIV+ people, meet every Sunday and provide counselling and financial support. I wish to reach out to as many people as possible."

TESTIMONY III

I would like to share some of my personal experiences. I grew up happily with my parents and studied up to eighth standard. Then, I stopped studies due to financial constraints. My parents died when I was quite young, leaving me unsupported. When I was in that state, I married a man and started living with him. He lived with me for a little while and after I had a son he left me for another woman. I was left alone with a child and had very little support from my own community. Then, I met an acquaintance and asked her for help. She suggested that I should go with her to find a job for myself. Soon, I found myself in a brothel. I stayed there for sometime. I found it impossible to run away from there. I was able to stay there with my son. One day, after a police raid, I was taken to the vigilance home. After two months at the vigilance home, twelve of us were tested for HIV (in 1986) and were found to be positive. None of us knew what it meant. We were only told that it was a new disease that could kill us.

Life became very difficult for us as we were treated very badly. Food was served through the windows and we were not allowed to meet anybody except the doctors who would test our

blood repeatedly. We were not even allowed to meet our children. We were kept in isolation for five years.

Then, a social worker who visited there apprised us of our true situation. She moved the court and finally we were released. I went back home and was alright for three years. Then, I started falling ill and was admitted into the general hospital for treatment. I met some people who were able to spend some time with me. Once I got better I found that I could not do much physical work. Now, I am attached to an NGO, a HIV/AIDS and Human Rights organisation and I feel much better.

> *"Everyone could support people with HIV/AIDS, comfort them and give them hope by mentioning that it is only a virus infection and that they will get better if they look after themselves. There is a grave necessity to induce positive thinking here."*

DISCUSSION NOTES

Q ***"Could you kindly tell us what you would expect us to do regarding AIDS?"***

R.

- *Help is needed in tackling quacks like the person from Kerala who claims that he has a cure for HIV/AIDS for a fee of Rs. 8 to 10 thousand. For poor and middle class people even Rs.500/- or Rs.200/- is a big amount. But, if promised a cure, they may raise the amount by begging, borrowing or stealing and get cheated by these quacks. When our Health Minister toured USA, he proclaimed that AIDS is not a big problem in India and that, there is a cure somewhere in southern India ! This statement highlights the ignorance prevailing in our society.*

- *The spreading of HIV infection in homosexuals is widespread. These problems need to be tackled in groups. Working with homosexuals is essential in order to prevent the fear of spreading the infection to others. Counselling should be provided to these people along with supportive environment. Mere counselling is not adequate. For example, people who are admitted into hospitals are treated very badly. Most often, important drugs are not available, they are refused adequate food and neglected by the hospital staff. It is amazing to find that even doctors are insensitive. This was proved in an instance where a patient requiring glucose drip was denied it and the same was administered to another patient. On enquiring the reason, the doctor and*

the nurses replied that all of them have children and cannot risk exposing themselves to the risk of HIV/AIDS infection.

Q ***"How frequently is the counselling done and what strategy can be adopted in the case of homosexuals?"***

R.

- *Homosexuals affected by HIV/AIDS work with the community of homosexuals by introducing themselves as belonging to the same community with similar behaviour. Then they counsel them about HIV/AIDS. The components of their intervention programme are :*

  a. One to one education about HIV/AIDS.
  b. Aggressive condom promotion. They use the same strategy while working with Hijras (eunuchs).

Q ***"What kind of strategies should we adopt ? Do you like your group to work with homosexuals. Are there any contacts already with similar groups in India ? Why can we not link up with similar groups elsewhere in the world ? Is there any possibility or need to network with a global network like GNP plus ?".***

R.

- *In Tamil Nadu we have contacted other towns and addressed the different groups of people to protect themselves from HIV/AIDS infection. We would welcome educational materials, slides and pictures related to the epidemic which would help us immensely when we address groups about HIV/AIDS. I would like to be in touch with a global network of people affected by HIV/AIDS.*

Q ***"What specific needs and support do you require from the managers ?"***

R

- *Financial support is needed to address the public meetings and self-support groups. Legal aid should be provided for these people for protection from the clutches of quacks who make capital out of an epidemic like HIV/AIDS. The three additional things required from organisations that work with people with HIV/AIDS are :*

  1. A short stay home or a place of shelter should be provided to accommodate people who are thrown out of their homes when they are discovered to be HIV+;

2. *Children of HIV+ people face a lot of problems concerning their education; some support is required to sort out this issue;*
3. *Another major problem faced by these people is lack of good nutrition.*

In India, while working with the homosexual men, their wives also need to be counselled and protected. These people get married according to the local custom.

Q ***"How long should the short-stay homes keep people and what is their future when they leave these homes ?"***

R.

- *It is observed that very often people who come to these homes show a reluctance to go back to their families. One of the probable reasons is that the families have not accepted them. In some of these cases family counselling helps as seen in about twenty cases who attended the family counselling sessions. The counsellors travel out of their cities into the districts in order to spend some time talking with the families. Family counselling is usually done by the same person who has been caring for the patient. In such cases, a short stay home would probably be beneficial. In some cases, people do not go back to their homes.*
- *Another important issue is that of safe sex. It is immaterial whether one has HIV/AIDS or not. Most humans react strongly to the question of whether the person concerned has HIV/AIDS or not. People desirous of working with HIV+ people should have an open mind.*

CLARIFICATION REGARDING AIDS COUNSELLING

Q ***"Which team would be more effective - HIV+ counsellors, non-positive counsellors or a mixed team consisting of both ?"***

R. *While talking to a HIV+ if he/she identifies himself/herself as a positive person, it helps the new person in identifying himself/herself with the counsellor. Y feels that a HIV+ person makes a better counsellor.*

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CHAPTER 7A

AWARENESS OF HIV/AIDS - A STATUS REPORT FROM ORISSA*

Presented by Mohanty P.K, Panda B. Bisoi S.

INTRODUCTION

The epidemic of AIDS is a health problem of great dimensions. In our country, it poses a serious threat and an unprecedented challenge to our public health system. It can spread over large sections of the population paralysing the socio-economic stature of the country and all its states. Asymptomatic infection with HIV/AIDS is more common than the disease which can progress fast resulting in a wide range of adverse immunological and clinical conditions. HIV infection is clinically classified as AIDS related complexes (ARC) and HIV neurological diseases (Dementia).

WHO estimates that a large segment of Indian population are or will be infected with HIV/AIDS, thereby increasing the number of HIV/AIDS beyond our estimate. Since many people are already HIV+, there is no way to prevent these cases turning into AIDS. Diagnosis and reports of cases have not been done in many areas hence the reported number of cases represent only a fraction of the total number of cases. Now, there is a grave realisation of the enormous implications of HIV/AIDS in terms of human suffering, social impact, economic loss in addition to the cost to health services everywhere including the State of Orissa.

Orissa, which is already beset with other communicable diseases, now adds HIV/AIDS to its list. The number of cases of maternal mortality and infant mortality are higher in Orissa than in its neighbouring states. Places of tourist interest such as Puri, Bhubaneshwar and Konark have witnessed an increase in the number of cases creating panic among people. Factors like migration of bonded labour from other states have added to the prevailing cases in the state. Increasing use of intravenous drugs and sexual relationships with unknown people have also contributed to it. In Orissa, the total number of tests done to detect HIV/AIDS was 62,835 (up to May 1994) of which 30 were HIV+ and 17 were confirmed by Western Blot analysis. Two had progressed to full blown AIDS and one died recently.

People from different walks of life have responded to this pandemic by showing a great interest in working for its prevention. A lot needs to be done in areas of social, epidemiological, cultural, economic and behavioural factors based on community based responses and the basic

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* This paper includes the presentation by Dr. P.K. Mohanty and Mr. B. Panda and the responses by Dr. S. Bisoi.

principles of public health, particularly in the absence of an appropriate medicine. Great attention has to be given to health education, mass mobilisation in order to generate public awareness as a strategy for prevention.

Orissa is a coastal state with the Bay of Bengal on the eastern border, bounded by West Bengal and Bihar on the north, Madhya Pradesh on the west and Andhra Pradesh on the south. The state covers an area of 1,55,707 Sq. Kms. with the second largest tribal population in the country constituting 23.43% of the total population of the state. Literacy rate is only 34.4% less than the national average of 39.42%. Factors like illiteracy, under nutrition, communicable diseases and genetic disorders like Sickle Cell anaemia, thalassaemia accompanied by poor health service delivery system are matters of great concern.

The major medical facilities in Orissa state include PHCs, CHCs, district headquarters, hospitals under the Directorate of Health Services under the government of Orissa in addition to three medical colleges, and a Unit of the ICMR - Regional Medical Research Centre. The industrial sector of Rourkela has only one large hospital.

DISCUSSION NOTES

AIDS SITUATION IN ORISSA

In Orissa, public awareness regarding HIV/AIDS is woefully lacking when compared with other states. But, the situation is quite serious. The location of the state, influx of outsiders and migratory bonded labourers have added to the incidence and prevalence of STDs in the state. The incidence of STDs and HIV/AIDS has also increased by unbridled sexual relationships both homosexual and heterosexual in addition to widespread use of hard drugs accentuated by unemployment, hunger illiteracy and inadequate knowledge of safe sex among the youth of the state.

Both Governmental and Non-Governmental Organisations play a very important role in bringing about public awareness as a measure of prevention of the pandemic. NGOs like Orissa Voluntary Health Association (OVHA) took initiatives to support members and non-members in planning and implementing AIDS awareness programmmes in the state. They have also prepared a data base of all NGOs working in the field of HIV/AIDS along with other details.

The Orissa Government has spent a total of Rs.80 lakhs, of which Rs 20 lakhs has been spent on NGOs and a few lakhs on blood banks and STD clinics. There are adequate funds for all blood bank officers and laboratory technicians of the 15 STD clinics working in the HIV field.

Each STD clinic was allotted Rs.3 lakhs for medicines and purchase of the latest equipment. Another voluntary organisation has been working on intravenous drug users and migrant labourers.

OVHA also conducted a survey through a questionnaire sent to all NGOs working on the field. The information gleaned from these questionnaires was put together to get a clearer picture of the situation.

All the risky areas prone to AIDS are being covered by these organisations. The Action Group encompasses 12 organisations at Block level, 19 organisations at district level and 2 organisations at state level. It also comprises of 1 hospital, 1 clinic and 31 voluntary organisations. The Christian Hospital has expressed a strong desire to initiate some action on identification and management using all its facilities.

Some organisations are working with the commercial sex workers in Bhubaneswar without achieving much besides promoting condom use and educating them about STDs and AIDS. The basic activities carried out by different organisations include awareness programmes through seminars/workshops/training, information, documentation and screening for HIV/AIDS. The vulnerable groups identified by organisations include sexually active people like the military and paramilitary personnel who are staying away from their families. They have responded well to awareness programmes which are being carried out for the benefit of commercial transport workers as well. Information about HIV/AIDS is also imparted through posters in different languages.

Some dhabas have agreed to distribute condoms. Work is also being carried out with "mobile" sex workers who are found at Calcutta, Cuttack and Bhubaneshwar.

After working with HIV/AIDS programmes, organisations have listed various problems encountered during the course of their work. They are:

* Ignorance of the public about HIV/AIDS;
* Ignorance about safe sex;
* Widespread prostitution;
* Migration of bonded labour;
* High incidence of STD.

They also reported several positive responses of people from various walks of life to the various awareness HIV/AIDS programmes. As regards blood transfusions, it is known that

people are getting untested blood. Even after 50 years of Independence, Orissa ranks first among the states in India in terms of poverty levels. There is a necessity to determine whether the problem can be related to remote areas of the state and probed to check about the spreading of the problem due to the migration of the populace to other places for better economical prospects.

Discussing the issue of the manpower, the representatives of NGOs reported that they are well equipped with personal support including medical personnel such as doctors, nurses, ANMs and other Health workers and infra-structural support. They concluded that innovative methods need to be adopted to bring about attitudinal and behavioural changes.

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CHAPTER 7B

A STATUS REPORT FROM ORISSA

WORKSHOP GROUP REPORTS

REPORT: GROUP I

Discussion on broader development concerns and HIV intervention.

Our group felt that migration factor could be controlled by providing developmental activities like income generation programmes. Most of these people migrate to other places mainly due to poverty and other economic conditions. The second factor is male dominance. The women are passive and are unable to take any decision regarding their sexual relationships. So, the NGOs play an important role in educating the women's groups regarding these aspects.

Another reason could be the destruction of natural resources and depletion of forest resources, due to which we are moving more towards a capitalistic or industrialised society and this change in lifestyle is affecting the health of the people.

The field of HIV/AIDS is quite new and not much knowledge has been gathered. Hence, it would be better to get some assistance from organisations who have more experience and knowledge in this area.

REPORT: GROUP II

This group also discussed the same issue and expressed the following views:

1. HIV/AIDS intervention should be integrated with the existing developing programmes.
2. Dissemination of information to the grassroot level organisations and to small groups should be done effectively.
3. The specialised agencies should provide technical support like training, advocacy and networking.
4. HIV/AIDS problem should not be dealt in isolation but incorporated with other problems like unemployment, and poverty for it to be successful.
5. Some NGOs felt that more than HIV/AIDS prevention, availability of food is their priority problem.

The other group members felt that as the migration of poor people from rural sectors and tribal zones is on the rise, women in distress and despair have resorted to earning an income through commercial sex.

Introduction of appropriate education on sexual behaviour for all groups should be undertaken. A comprehensive training for the youth groups through the introduction of audio-visual aids, print materials or booklets in their own languages should be imparted. Integration of HIV/AIDS components into the existing health care programmes would be more appropriate and effective.

REPORT GROUP III

This group discussed the following issues. There are taboos attached to sex, STD and HIV/AIDS though the latter is almost unknown. When people suffer from STDs, they hesitate to see the doctor and seek the advice of their friends or paramedics. Hence, people should be educated to seek out proper medical personnel to get the right treatment. It is a common trait in Muslim women that they shy away from the male doctor for various reasons. In this context both men and women should be educated to accept specialised services, irrespective of the sex of the doctor.

There is also a need to develop a good rapport with the local leaders like Mahila Mandals, traditional leaders, teachers and nurses to educate them on issues like HIV/AIDS and STDs. They in turn can motivate other people towards treatment.

We should have a total community approach rather than a target oriented approach to begin with. In this context, introduction of traditional folk songs on the issues of STDs would be a very effective way to educate the rural illiterate women. The culture and tradition of the communities should not be forgotten.

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CHAPTER 7C

RECOMMENDATIONS

During the consultation, a lot of innovative and practical suggestions were mooted.

* AIDS is not confined to any caste, creed, sect religion or social status. It is not only confined to the high risk groups, but is also spreading to the general population.

* Educating people about AIDS, both in schools and community, has to become the chief approach in prevention.

* Sexually transmitted diseases increase the risk of sexual transmission of HIV. Therefore, it is essential to integrate sexually transmitted diseases control and AIDS control programmes at all levels in the country.

* It is essential to draw gender based responses that focus on how the different social expectations, roles, status and economic power of men and women affect and are, in turn, affected by the pandemic.

* Grave gender disparities exist in this epidemic, where women continue to bear the brunt in addition to being highly vulnerable to infection.

* Sexual and economic sub-ordinations of women fuel the pandemic. It is essential to bring about a major change in the social and economic status of women by improving their social conditions, providing better income-generating activities along with savings and credit facilities.

* Prostitution needs a special mention, because of the vulnerability of this group to this illness. The voluntary sector and the women's movements must step up their efforts to intervene to combat the spread of the disease in these communities.

* Counselling is another area needing a lot of attention as our country's efforts are quite inadequate. It requires a lot of training and other related inputs.

* Focus on human rights and discrimination experienced by HIV+ persons is particularly important, because HIV infected persons are denied jobs, housing, medical care and health insurance.

* Blood safety is another important component in prevention. It is important that any unit of blood to be used for transfusion has to be mandatorily tested against HIV/AIDS.

* Implementation of sex education in schools and colleges is important to make the youth aware of the mode of transmission of the virus.

* It is urgent to make the political leaders aware that, if they act appropriately and promptly, they could avoid the serious consequences already being seen in other parts of the world.

* We need to involve HIV+ people in our control efforts within communities.

* There is a greater need to build alliances and networking with other organisations, particularly NGO sectors and other government organisations across the globe so that they can share the common interests and build effective preventive measures for this epidemic.

* Gay Rights should be considered as Human Rights.

* Building effective alliances based on mutual respect between men and women remains the greatest challenge for stemming the pandemic.

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CHAPTER 8

HIV/AIDS AND THE HUMAN CONDITION: WHOSE CONCERN IS IT ULTIMATELY?

Shobha Raghuram

One and a half decades of accumulated experiences with HIV/AIDS is a long enough time for securing commitment from governments, organisations in civil society and medical establishments towards preventive work, long-term strategies and the provision of reliable support centres. However, not only has the issue been marginalised but worse still, more than two-thirds of people living with HIV have difficulty accessing health care, employment and securing their fundamental rights. While the media has highlighted the problem in several countries, it is also true that governments have not shown the required political will to operationalise in mainstream-planning the capacities for communities to prevent and to cope with the epidemic. The 'denial syndrome' is causing major tragedies with varying degrees of deprivation. The economic devastation is a large part of the story. If the cost of diagnosis can vary anywhere between Rs.450 to Rs.10,000 (blood testing, MRI etc.) it does not take much imagination to get an idea of what diagnostics, drugs, consultations, hospital fees all included might cost. Sero-positivity ratios per thousand are peaking, legal safeguards continue to be virtually non-existent for the protection of those ill with HIV, for sex workers and for homosexuals. Statistics hardly reflect the intensity of discrimination, rejection and physical hardship endured by many in India and elsewhere. Forecasters predict that the centre of gravity of HIV/AIDS is going to shift from Africa to Asia... India, Cambodia, Myanmar and Thailand witness ½ million fresh cases of HIV per year. The number of positive children and women, often cast out of their families and exiled by medical institutions and welfare homes is on the rise. For the very poor the social rejection is as fatal as the illness. A centre in Madras found that about $^{1}/_{3}$ of the men and half of the women who came to it after testing positive were earning less than Rs.500 per month! If the state and a large number of institutions in civil society render invisible this issue, then, whose concern is it ultimately? One may well rephrase the question and dwell on responsibilities.

In trying to interrogate some of these issues, during the consultation, there were many innovative concepts, practical suggestions and challenges that participants offered. What has been difficult in a discussion of the problem is that it touches the core of our lives and those of others. HIV/AIDS is a difficult area of work because it involves the personal realm. Most of us who have been involved in developmental work have been more adept at handling issues in the public domain.

As this illness has begun to appear with a very significant profile, having profound consequences for the human condition as a whole, it is necessary that we get off the board of the kind of disciplines we were used to, and break the barriers of the private and the public. The personal testimonies were just the tip of the iceberg - trying to move across to a community at large, and to be able to speak about HIV/AIDS, about sexuality, and coping strategies. I have been involved in the development sector for the last thirteen years and I have seen the difficulties development workers have faced in moving from the public to the private domain as many became affected with HIV. What the contributors are suggesting is that HIV/AIDS is not just a health issue, and, it is not only a development concern and it is more than only being a human rights issue. It is not just a legal matter and it is not just an ethical matter. It is all of this in fact and more. The interrogations have slowly moved at multilateral levels and I think, what has brought all of us together has been this very common concern.

HIV/AIDS as a development issue has been a concern of some development organisations, which are trying to address the major structural imbalances of the problems of the poor as a whole - both rural and urban, the economic contradictions, the problem of food scarcity, the problem of vulnerable sections, loss of common property resources etc. Most of these areas have been very traditional development concerns, and there is agreement that this illness will have a much greater impact on this very constituency. Therefore, it is a problem that has taken roots here. There is enough of work within voluntary organisations to show at least part of this reality in the last couple of years. There are also organisations solely devoted to prevention and training work in HIV/AIDS. Major voluntary organisations are alarmed by the dwindling resources for public health and the deteriorating conditions prevailing in public health centres in India. From the first Five Year plans there has been an extremely steady, minimum maintenance budget for health. There has been a lack of specific focus on social concerns, and consequently the budget planning has remained extremely insignificant. It is true that poverty related problems, especially the health concerns of the poor, whether it is anaemia for poor women, dehydration, malnutrition, malaria, tuberculosis etc., there is diminishing budgets for these issues. These primary health care centres even today are not able to have the 20 essential drugs that they should have. After the Reform Policies were initiated in 1991 multilateral lending institutions are increasingly, playing a major role in financing prospects in health care. And yet, it appears that many donors are pulling out of HIV/AIDS related work and it is likely that there will be a decline from the present level of roughly $300 million assistance annually in HIV related aid and technical assistance. **Revitalising the present health care apparatus and integrating HIV/AIDS prevention, rehabilitation and counselling work at the PHC level needs to be high on the agenda.**

Some years ago, the Government of India officially recognised HIV/AIDS as a problem affecting India and negotiated World Bank loans for HIV/AIDS. Health activists at that time felt that the traditional concerns were being completely submerged, forgotten or sidelined and there was a genuine fear that every voluntary organisation would somehow move on to overnight begin HIV/AIDS related work, neglecting the other activities of equal if not greater concern. One of the requirements I believe is to take a much more studied view of this problem, look at the limited resources as it were, and secondly, examine how these illnesses are often interlinked with HIV itself, right from a clinical perspective on to the perspective of the poor who have to cope with the problem of survival from day to day.

It has also been a fact that coping with the HIV/AIDS illness and strategies for prevention may be quite different for South countries from North countries given the kind of political, economic, and cultural realities at both local and global arenas. Therefore, it is an urgent problem for south countries like India, while taking full cognisance of exactly what the Government's responsibility is in social security concerns, to also take more seriously this issue and actually plan the strategies and interventions. People who have worked in some of the larger immunisation programmes in India and in primary health care centres have to be involved.. All of this includes the breaking down of the vertical structures that exist in medical institutions and including paramedical workers at grassroot level. This kind of a national plan is necessary, but the government is not in a position right now, to be able to provide that. I think that this is where the voluntary sectors who have particular sensitivity to ground realities may have to design the strategy and lobby for implementation.

The lack of reliable data related to HIV/AIDS, exacerbated by the 'underground' nature of the problem has further contributed to distorted perceptions among people of this illness. NACO has reported a 7.37 per thousand sero positivity rate with a sample base of 26,79,033. The number confirming to Western Blot is around 19,754 and full-blown AIDS is 2009. Experts say that better reporting could show a 10-fold increase. Difficulties in data bases include 20 million people internally migrating in developing countries. The migrants live on the fringes of these cities, where there has been tremendous violence, communalism, often because of shifting populations and socially depressed class status with a predominantly young male population. It is very important that we be able to work with NGOs for whom the constituency are internal migrants.

Many participants agreed that HIV/AIDS really cuts across all development concerns and across class, communities and caste. The problem of equality, social justice, human rights etc., is a much larger concern than one's own community and its preoccupations because repeatedly we were asked, "whose concern is it, ultimately?"

Among developing nations, at least on the issue of official cognisance of HIV/AIDS, India is far ahead of many other developing nations and governments. We'll have to look for allies and really work with them. India offered to host the Asia-Pacific AIDS Congress when Singapore had refused to do so. It is true today that in Thailand, Nepal and in many of the adjoining countries there is tremendous state repression on the data, because it would affect their tourist industries. There is no real information coming and there is significant disinformation campaigns going on. The work that must come from the public interest institutions is to negotiate consistently and persistently with the ministries and so on. Strong public lobby platforms are necessary.

Obscurantism and the social setting of traditional cultures has to be addressed. What I believe, however, to be on the anvil is that the options must be provided and the obscurantism must be exposed. There is myth, there is reality, and there is fact. They tend to reinforce the same political patriarchal cultures or the same equations of power. This was particularly evident when women's organisations worked with the Government on the population policies document of the United Nations during ICPD. Fundamentalist religious groups objected vociferously to all references to sexual and reproductive rights. Women are articulating their demands to address reproductive health rights, their rights over their bodies, and their full participation in all economical and social justice agendas.

It is quite unfair to believe that it is only women's interest groups or NGOs dealing with the "classical" women's issues that are concerned about women and HIV. There is a basic systemic problem in this society: falling sex ratios, extremely unequal access for women to all services of Government, continued loss of control over their lives, (whether it is spacing of their children or the choice of reproductive technologies etc.) and limited participation in decision-making. Given all of these issues it becomes paramount then to recognise and acknowledge, that women have been much more seriously victimised in this illness and especially in the area of STD. Women must have access to information, to enable them to make valued decision-making on their own. Men must acknowledge that they are as much a part of the problem and not apart from it. Patriarchy, obscurantism and fundamentalism can reinforce not only the victimisation of women but also drive underground the problem of HIV/AIDS itself. Women in prostitution often perceived as "sectors of spread of HIV infection" have been at the receiving end of criminal physical and mental abuse, harassed by male clients, the legal system, and police personnel. This has to stop. High on the agenda is the securing of social justice for women in prostitution.

Lastly I come to another neglected area of affirmative work and that is counselling. It deals with how we help others to live with these issues and problems, whether it is in safe sex counselling, pre-test or post-test counselling. This requires tremendous commitment and professionally trained

personnel. Vijay Thakur calls this the "reconstruction of self-affirmation".

After so many years of living with this illness, large scale tragedies as in Uganda etc., why is it that systems are still not open, transparent and benevolent? When statistics wear the mask of myths something is wrong somewhere. The tragedy has been, that we have not found the solutions quick enough. The fact about HIV/AIDS is that it is totally preventable and it is possible that those who live with it, can find greater chances of longer survival strategies. Deserving of attention is the neglected matter of resolving the powerlessness of those afflicted. The systems are pushing people who are ill to the peripheries of existence, endured in sheer passivity.

We cannot really start a major campaign or start major strategies for survival, if we are not able to be partners in the problems of the protection of the ill, their identity and their resistance to violations of human rights. "How did you get it? Where did you get it from? etc." are run of the mill, thoughtless questions people face. The human condition matters but on what terms and whose terms is worthy of a rights' agenda determination. The fundamental freedom of people and institutions in civil society include the right to confidentiality, the right to their sexual preferences and the right to choices. It also include rights to hospital care, and, non-discrimination for employment.

We have to use all available public platforms to talk about these development concerns, and highlight these issues. We find at local levels, local solutions. As one of the reports suggested we cannot invent problems or import solutions for we have to allow them to emerge from the field. We have to be sensitised on a fairly mass level and the many vital non-governmental initiatives in the country need to be replicated. If we look at the numbers, they may appear small, but it is the qualitative focus that people have put in and their commitment that brings out the specificity of HIV/AIDS.

I conclude with the underscoring of the need for political realism: distinguishing fact from myth and operationalising preventive strategies. The time is really coming where people would be willing to come and speak, but we have to greatly respect that confidentiality. And therefore, perhaps we come back to the main question which has been repeatedly posed "whose concern is it, ultimately?" But the answer to that has equally come from the participants that every human condition is everyone's concern: It is not of any one organisation's or institution's alone or a particular sector priority. Perhaps at this point it is important that the rest of what has been unsaid but was understood remains in silence, because one has to learn, to cope, to prevent and to stand by those challenged by yet another apparently insolvable problem.

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SECTION III

CHAPTER 9A

INTRODUCTION TO MEDIA AND HIV/AIDS

Since the beginning HIV/AIDS has attracted wide-spread media attention and, the media has been quite successful in raising awareness that there is a disease called AIDS. The association of AIDS with sexual behaviour, particularly in the gay community, roused curiosity and the incurable nature of the disease raised much fear. In fact, much of the early messages were directed at raising fear. For instance, the dramatic grim reaper campaign in Australia[1], showed a scythe carrying skeleton bowl over human skittles. This campaign received much attention. It fostered debate on AIDS and increased a demand for condoms. At the same time it evoked great fear and created a high demand for testing and other services that could not be met. Discrimination against those who had HIV/AIDS intensified. Educators who had worked hard to promote the message that AIDS was preventable and people should adopt responsible sexual behaviours were appalled by the subliminal message that equated sex, AIDS, and death. A similar campaign was carried out in India during the early 1990s. Government posters showed a doctor standing over body and the caption read: There is no cure for AIDS. Another poster showed a noose, and AIDS written in bold letters. Fear raises denial, avoidance and the need to blame.[2] The challenge is to develop messages that evoke concern and vulnerability and combine it with practical ways of modifying high risk behaviours which empower people. Messages should end with hope and practical ways of changing behaviour or seeking help.

HIV/AIDS raises many issues that need to be handled sensitively. The connection of HIV/AIDS with sexual behaviour brings into question many strongly held beliefs about the nature of society and values. Many Indians, especially the professional and middle class, often generalise from their own experience and come to the conclusion that all Indians think, believe and behave as they do. They reinforce the dominant world view and do not allow for differences in customs and life styles of different sub-groups and minorities.[3] Many times media has not respected the privacy of people with HIV/AIDS. Breach of confidentiality has created untold trouble to people who have shared their experiences in the hope of preventing others from acquiring HIV and in the hope that others in a similar situation will gain from their experiences. Media needs to be more accountable, and avoid sensationalisation and stereotyping. While such stories may sell, they are not credible. On the other hand, good,

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[1] Winn, Margaret The grim reaper: Australia's first mass media campaign in WHO (1991) *AIDS Prevention and Promotion - Facing Sensitive Issues*, WHO, Geneva, pp. 33-38

[2] Moynihan, Maeve. " Emotional responses to the AIDS Pandemic" in WHO (1991) *AIDS Prevention and Promotion - Facing Sensitive Issues*, WHO, Geneva pp 3-8.

[3] For a discussion of the influence of culture on Asia perception of HIV/AIDS and its depiction in the media, see Wollfers, Ivan "Culture, media and HIV/AIDS in Asia, *Lancet*, 349, 52-54, January 4, 1997.

responsible human interest stories attract readers, give food for thought and offer alternative strategies for prevention and care.

These stories need to be written with care and choice of words is important. Media routinely uses words like "scourge", "plague" to describe AIDS, words that have strong negative connotation, that tinge peoples reaction to PLWHAs. Scientific facts like the distinction between HIV and AIDS should be respected and depicted appropriately. Often people with HIV are labelled as "AIDS sufferers or AIDS patients ," giving the impression that everyone with HIV is suffering or is a patient, while in reality people with HIV can lead productive lives and contribute to society. Because of the indiscriminate use of AIDS in the media for HIV infection, many people think that they will have AIDS as soon as they are infected and decline rapidly. Other words like "victim" lead the reader to think that the disease is not preventable, or "innocent victim" makes one think that other PLWHAs are "not innocent" or "sinful."

Recent developments in the treatment of HIV/AIDS receive good coverage in the media. However, this information is presented as though the treatment will be available tomorrow. The time lag between discoveries, clinical trials and approval for human use is seldom considered. Whether these treatments will be accessible and affordable to people in developing countries is not given attention. This gives PLWHAs and their families hope, which is essential, but also raises unrealistic expectations and gives rise to a feeling of deprivation.

The media needs to cover HIV/AIDS issues from a developmental perspective. This will avoid victim blaming and link HIV to the socio-economic structure and the inequities embedded in this structure. If the aim of media is to raise a national debate on HIV/AIDS both in terms of prevention as well as care, the media will have keep this issue on the forefront.
NGOs can play a lead role in:

1. Providing media with information that links HIV/AIDS to general development;
2. Develop strategies to make the media more gender sensitive;
3. Provide accurate information on HIV/AIDS transmission and the people who are at risk;
4. Identifying and evaluating low cost folk media;
5. Combining effective media with interactive education to bring about behaviour change necessary for preventing HIV/AIDS and practising safer sex.

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CHAPTER 9B

REPORT ON THE WORKSHOP ON HIV/AIDS, DEVELOPMENT AND THE MEDIA

(Compiled by Cynthia Stephen with inputs from Centre for Education and Documentation (CED)

Jointly organised by Hivos and the Centre for Education and Documentation (CED), Bangalore at The Indian Social Institute, Benson Town, Bangalore from 25-27 March, 1996.

The issue of HIV/AIDS has shifted from being viewed as a purely health-related one. It is now a Development Issue, with impacts in the areas of Human Rights/Ethics and Gender Policy. While Governments have responded to the health aspects of the issue, it has generally been left to NGOs and groups of concerned citizens to work on the other aspects. An inadequate understanding of the issue, for instance, has led to government, health and legal machinery violating the basic human rights of HIV+ persons.

Sensational, alarmist reports in the media have contributed to popular misconceptions about the syndrome. Thus, it was felt that activists, community-based workers and development communicators in charge of NGO newsletters should be brought together to look at HIV/AIDS in its various aspects. In particular, it was felt that they needed to keep abreast of happenings in the area, so that they in turn would be motivated to cover the issue in their publications. This would help field-based persons to respond appropriately to the issue, when they encountered it in the field.

Thus, Hivos and CED came together to organise a workshop on HIV/AIDS and the Development Media. (The term "Development media," while broadly defined as non-mainstream media, actually refers to NGO newsletters in the context, and is used as such in this report). About fifty participants including some staff of Hivos and CED and the workshop co-ordinators participated in the workshop. While the first two days were devoted to studying the various aspects of HIV/AIDS in great detail, the third day focused on various aspects in the planning, production, dissemination and funding of NGO newsletters. For the purpose of this report, we documented the first two days in a somewhat greater detail than the third. Participants were drawn from NGOs working in health community, development and communication from all over the country. The resource persons on the issue of HIV/AIDS included the following:

* Dr. N.H. Antia, Community Health and Public Health expert and founder of the Foundation for Research in Community Health
* Dr. I.S. Gilada, founder of Indian Health Organisation; medical doctor and HIV/AIDS activist
* Dr. Shobha Raghuram, Social Scientist
* Ms. Shobha Agarwal, Activist lawyer
* Ms. Shyamala Nataraj, Journalist and AIDS activist

Two others shared testimonies of personal experiences.

THE INDIAN SCENARIO

The background note circulated to the participants prior to the Workshop noted that the impact of HIV/AIDS was more severe in developing societies than in developed societies. In the west, it showed a gradually declining trend, while it was peaking in Africa. In Asia, it showed a steeply growing trend.

According to the National AIDS Control Organisation (NACO), there were 21,131 confirmed HIV+ samples out of a total of 27 lakh samples screened (end 1995). About 2095 had developed AIDS. The national sero-positivity rate was 7.7 per thousand. While official estimates put the number of HIV+ persons currently at 2 million, others put the figure at nearly twice that. Official projections indicate 5-8 million infected persons by the year 2000. Over 80% of these affected people are in the 20-40 age group. A study by the JJ Hospital in Mumbai indicated that 40% of those affected were skilled workers, contrary to the popular belief of "sex-workers and their low class clients" being the most affected. It also has grave implications for the economy if a large section of the skilled population is being affected.

HIV/AIDS AND DEVELOPMENT

1. HIV/AIDS AND COMMUNITY

Urban Centres with high floating populations show a higher incidence of HIV infections. Migrant workers working in these areas carry the infection back to the rural and tribal hinterlands during the off-season, exposing the women and children to the risk of infection. These vulnerable sections of the population already suffer the adverse effects of poor access to education, sanitation, health and social services. They also bear a heavy burden of household labour.

The community level impacts of HIV/AIDS include the costs of losing young parents in the productive age groups and the stress and risk to the emotional, mental and physical health of caregivers in families, mostly women. Children of AIDS patients would be orphaned, leaving them to be cared for by extended family or elderly grandparents. Women would be widowed and be responsible for the financial support as well as the upbringing of the children some of whom may be HIV+ themselves. The cost of medicines would go up, incidence of loss of income caused by frequent illnesses as the syndrome progressed.

2. HIV/AIDS AND GENDER

The gender aspects of HIV/AIDS were brought out well in the sessions chaired and facilitated by Shyamala Nataraj. While the details are covered elsewhere in this report, a brief discussion is given here. HIV/AIDS affects man and women in a vastly different manner. Heterosexual intercourse being the main means of transmission, the issue impacts the very private domain of interpersonal and gender relations. Social attitudes and norms deny women the autonomy to make decisions about their sexuality and bodies. Political and economic powerlessness robs them of the capacity to negotiate terms for sex, let alone safer sex. The physiology of women, including the larger mucosal area of the body reproductive tract, the fact that semen and cervical fluids are retained in the tract , and the greater incidence of undetected reproductive tract infections makes them more vulnerable to the infection. The germs travel much more efficiently from the male to the female rather than vice versa.

3. HIV/AIDS, HUMAN RIGHTS AND ETHICS

HIV/AIDS being linked with sexuality or sexual behaviour has provoked strong negative reactions on the part of the public, the government, medical staff, the media, and the legal system. In the initial stages at least the syndrome was associated with "intravenous drug users, prostitutes and homosexuals." Traces of the stigma still linger though the groups do not necessarily figure in the growing numbers of newly infected persons.

In general, the extreme reactions of people when faced with HIV/AIDS and of the public to the issue itself points to a need for a sensitive handling of the information. Maintaining confidentiality, anonymous testing, pre- and post-test counselling by experienced counsellors, protection of the rights of HIV+ people in terms of employment, non-discrimination in health care, supportive counselling for the family: all these are imperative, given the spreading nature of the problem. Often, the media is also responsible for the spread of misinformation,

sensationalism and insensitive reporting which puts HIV+ persons into real hardship and even into risk of livelihood and life ! The legal system also needs to be made aware of the implications of the HIV/AIDS issue. Groups such as the AIDS Atyachar Virodhi Manch in New Delhi, South India AIDS Action Programme in Chennai, and the Lawyers Collective in Mumbai have worked on the issue, and more of their work is discussed in the report of the proceedings of the workshop which follows.

PROCEEDINGS OF THE WORKSHOP

Session 1	**:**	**Working with Media for HIV/AIDS Awareness The IHO Experience**
Chairperson	**:**	**Joe Thomas**
Resource Person	**:**	**Dr .I.S. Gilada**

Dr. Gilada was invited to speak at the first session. He gave a lively talk, made more interesting by a slide presentation, using visuals of field work initiatives undertaken by IHO, a voluntary organisation that he founded four years ago.

Dr. Gilada's experience with HIV/AIDS began during his work as a doctor in the Skin & V.D Department of JJ Hospital, Mumbai. When HIV/AIDS first appeared on the scene in Mumbai in 1986, there was so much of paranoia even among the medical profession. He showed a slide of the outfit worn by the doctors who did the postmortem on the first patient who died of AIDS-related complications. The outfit consisted of double gloves, full-face masks and two surgical gowns, one worn over the other ! Even this equipment had to be provided by him, as the patient died in his department. The pathologists almost to a man refused to conduct a postmortem but the Chief of the Department came to his rescue and enabled the postmortem to be done. However the picture was different now due to a better understanding of HIV and increased awareness. The pathologist who conducted the first postmortem is now considered something of an authority in the subject.

Dr. Gilada showed a number of slides of posters and other visual material developed by the IHO to spread HIV/AIDS awareness not only among the general public but also among the sex workers in the red light districts of Bombay. IHO has facilitated an active self-help group called Saheli, exclusively for and by sex workers. The volunteers in this group fanned out among their peers to spread the message of safe sex and to promote condom use by sex workers and their clients. The condom distribution was also undertaken by these sex workers, called Sahelis. The women also participated actively in publicity campaigns and worked to coin

catchy slogans. Culturally appropriate messages were generated for use during popular festivals such as Ganesh Chaturti, Navratri, etc. Mythological figures like Lord Ganesha and Narada were used to promote HIV/AIDS education in posters. Wall writings were found to be a low cost and effective means of publicity. Songs with a message set to popular film tunes were also used. The 'Sahelis' also ran a Hindi magazine called 'Saheli' which is also written and produced by themselves.

Dr. Gilada also touched upon efforts at advocacy using the mass medias as well, though IHO primarily used direct media such as posters. HIV/AIDS was placed in its social and economic context by linking its occurrence with gender, human rights, powerlessness, etc. He also stressed that while much negative publicity was given to the failure of some hospitals and refusal to treat some AIDS patient nobody bothers to note that even full AIDS cases were treated routinely in most hospitals. He stressed the need for the media to highlight positive stories on the issue to counter the aura of negativism surrounding HIV/AIDS.

Session 2 : HIV, Law and Ethics
Chairperson : Shyamala Nataraj
Resource Person : Shobha Agarwal

Shyamala introduced the speaker by first talking of her personal knowledge of the founder of the AIDS Atyachar Virodh Andolan, an informal group of concerned citizens first founded in Delhi by Mr. Siddharth Goutham. Shyamala said that during the lunch break she had been approached by several persons in the group who had requested that a dialogue be held regarding a controversial vaccine trial in Mumbai of which Dr. Gilada had personal knowledge and involvement. Ms. Shobha Agarwal was involved in litigation on the same issue. She asked the group whether they would like discussion on this subject. There was consensus that after Shobha had made the presentation, Dr. Gilada could respond for ten minutes and after this, an open question and answer session would ensue.

Shobha shared a brief history of the work of the Manch which was started in 1988. The group met at a coffee house every week and each member paid their own expenses. They accepted no funding for any activities. The group had conducted surveys and studies on social and legal issues and published reports on them, all at the members' own expense.

Shobha Agarwal herself was presently involved in filing a case in the Supreme Court against certain organisations who had conducted AIDS vaccine trials in the country. She summarised the case as having been against an AIDS clinic run by a charitable organisation in Mumbai, which had allowed

ten of its patients to receive vaccines which were under experimentation in the US. Apparently, the clinic was associated with IHO and Dr. Gilada was himself involved in giving pre-vaccination counselling to the recipients. IHO had also made arrangements for the doctor from America to bring in the necessary materials and equipment providing authorisation letters for Immigration and Customs authorities.

The alleged illegal nature of the testing was due to the fact that the substance brought in for the test was still awaiting approval by the Food & Drug Administration for testing on animals in the US! They had not been cleared even for testing on animals, let alone having been cleared for Phase 1, 2 or 3 trials on humans. In India, no drug testing is allowed except by research institutions approved by the government and private institutions have to get approval from the Drug Controller of India.This approval had not been even applied for. One of the persons "vaccinated" who was already showing AIDS symptoms at the time of the trial had died, but whether the death can be linked to the vaccine directly, though there may be some correlation, is yet unclear, said Shobha. She circulated a copy of a press clipping giving information on the incident.

In response, Dr. Gilada clarified that the clinic in question was not directly managed by IHO but had its own decision makers and they had decided to associate themselves. While it was true that he had spoken to the patients, Dr. Gilada said that when he heard that these vaccines were not approved, he asked the foreign collaborators to agree to a protocol and sign it. They refused and then IHO and Dr. Gilada withdrew. He also stated that the persons living with HIV/AIDS who had undergone the test had their own self-help group. This group met and made an independent decision to go ahead and participate in the trials. As for the letter which was supposed to have been written by IHO, he said this was incorrect but that it was written by the doctor in charge of the clinic who had been in direct correspondence with the parties in the US. Dr. Gilada also alleged that one of the woman staff of the IHO who had suddenly stopped coming to work without notice or taking leave was found to have married the doctor from the US who had initiated the whole exercise. This fact came to light several months after the woman had disappeared.

In the question-and-answer session that followed, a number of questions arose regarding the legality of the trials; the fact that the Drug Controller was also liable to take action against those who erred; the nature of information made available to persons living with HIV/AIDS during counselling; whether such dilemmas as the decision to participate in risky medical trials were fair to the already traumatised AIDS patients the accountability of NGOs and medical establishments, etc. The discussion was heated in parts and after a suitable interval, the chairperson intervened and moved the discussion to other areas in ethics such as maintaining anonymity of HIV/AIDS patients; non-use of pictures or identifying information by media, the

desirability or otherwise of NGOs encouraging HIV/AIDS patients to openly faced the media etc. As an example of how not to do it, Shyamala Natraj showed a copy of a publication by Nexus Population Services which carried an article giving pictures of inmates of an 'AIDS Home' in Sangli and read out portions of the text which could cause bias and prejudice in the minds of the readers.

In the discussion that followed, there was a debate about whether it was right for NGOs and institutions to become judgmental or 'cagey' about information on HIV/AIDS; whether a code of ethics, even if self-imposed was a good idea etc. However it was agreed that there are certain established practices regarding disclosure of identity of AIDS-affected persons, mainly due to severe social backlash against those identified as AIDS patients. This should be followed in their best interest, it was felt.

Another key issue that came up was that of screening for HIV/AIDS: the tests were so expensive that universal or even large-scale screening was prohibitive. The more important question was the necessity at all of universal screening. Also, the handling of the information that one got from the tests was important. Who should be told- for instance, was it or was it not a breach of confidence if the spouse of a HIV+ individual were to be told of the HIV+ status of their spouse? Did the employer who frequently organised screening camps, have a right to know?

It emerged from discussion that as the issue mainly concerned the positive persons and the spouse, it was certainly better to restrict sharing of information only to them. Employers had no automatic right to know.

The economic implications of AIDS was also discussed. Shyamala pointed out that it was a very expensive proposition to provide care to terminally ill AIDS patients as they often suffered from many complications. Donors were reluctant to support such activities as it was a long-term commitment. Hence, funding for terminal care of AIDS patients was a real need.

This discussion was followed by the sharing of experiences of two HIV+ persons from SIAAP.

PERSONAL TESTIMONIES

X, a former sex worker, was one of the first few women who were incarcerated and force-tested for HIV in Chennai, prompting Shyamala to go to court to secure their release. Mother of a pre-school son at the time, she had been separated from him for five years while the case

was pending, which took about five years to fight successfully. She shared the trauma of being ostracized, abused and ill-treated by staff of both the General Hospital (GH) as well as the Remand Home in Chennai. After much hesitation, she spoke to a SIAAP Counsellor who visited regularly at General Hospital and offered to work for them in the field among sex workers, to promote safe-sex practices among them and to distribute condoms. She spoke of being picked up by police and being charged with soliciting even when she was on her distribution route. She revealed how media had disclosed her identity in an article in the Tamil press, which made it impossible for her to return home. X's story was shared with simplicity and conviction in Tamil and was translated into English by Shyamala.

Next came the experiences of Y, an activist of the Positive Action Group. He was able to communicate the real plight of the HIV+ individual. Speaking in Tamil (translated into English by Shyamala), he shared that his real concern in being involved in AIDS work despite the high personal cost was:

1. To give the message to parents and family members to deal with their young children with affection, so that they would not look for love outside the home and become victims of unscrupulous persons as had happened in his case.
2. To spread the message among homosexuals that they too were vulnerable to HIV/AIDS. At present, the homosexual community in Chennai and elsewhere, firmly believed that the infection travelled only through heterosexual transmission and they need not fear getting infected by HIV.

Relating his experiences, he said that he was unhappy at home because of constant nagging, even violence by parents. He played truant from college and spent time in a park. Here, he met a man who befriended him and gave him a lot of affection. Sometime later, he took him to his room and a physical relationship began. It was very intense and Y lost all interest in studies. He began to spend more and more time away from home. After several months, he began to feel that he was like a slave to this man and begged to be left alone. However, the man instead gave him an address and asked him to go there. "We have to do as we are told because they find out our addresses and details of our families. If we do not co-operate they come to our homes in a group and create a lot of trouble for other members of our family. To avoid this, and to avoid getting 'exposed' as a homosexual, one must co-operate," he said. At this place where the man sent him, there were many young boys and older men, several of whom were foreigners. A great deal of homosexual activity took place here. Y and other boys were asked to enlist other youngsters into this activity and they did. Most of these newcomers also had histories of disturbed family and personal life. Several months passed, and Y's mother began to talk of arranging his wedding. A friend and confidant advised him to undergo an HIV test. Y initially

refused the test as he believed that HIV could only be transmitted through heterosexual relations. Just to prove his friend wrong, he underwent a test, which turned out to be positive. He went to another testing centre and had a test done again; it was positive and confirmed.

"I was shattered" said Y. He contemplated suicide. He went back to his friend and shared his thoughts. His friend persuaded him to change his mind by telling him that death will not change anything but continuing to live and work to share the experience might prevent other young boys from a similar fate. Since then, Y has tried to do this. In one misguided attempt to raise public consciousness, he trustfully gave a detailed personal interview to a reporter from a prominent daily, requesting anonymity. But the reporter did a little legwork, got to know details of his family, etc. and printed the whole story. This caused terrible repercussions in his family. His father, after reading the newspaper, began to beat him black and blue. Y was bewildered as he had no idea that the reporter would do such a thing. His sister's husband also stormed into the house and tried to attack him. Some days later, his father tried to poison him.

A sympathetic doctor visited his home and counselled the family, explaining that casual contact would not transmit infection. But, none beside the mother accepted this fact and everyone left the house to live apart.

"I have got to go on doing my duty of informing people of whatever I went through. People with HIV have so many problems. They need financial support to meet medical expenses and moral support as they begin to fall ill more frequently. They worry about their families' future. A number of us have come together and formed the "Positive Action Group," a self-help and support group for positive people" said Y. He says that his main request to people is to treat children in families with love so that their emotional needs are met within the home. This is the best way to protect them from harmful influences, he feels. He pleaded with the participants to help him in any way possible to get the message across.

DAY 2 - MARCH 26, 1996

Session 3	**:**	**HIV/AIDS and Gender**
Chairperson	**:**	**Aarthi Pai**
Resource Person	**:**	**Shyamala Nataraj**

Shyamala opened her remarks by stating that behavioural norms based on gender did not only affect women negatively. Men also experienced being trapped in modes of behaviour reinforced by society. The main difference was that women were more oppressed by the system.

Rather than just confine the discussion to HIV/AIDS, she said that she wished to widen the scope of the discussion to include the whole gamut of health care, reproductive services and reproductive tract infections (RTIs) and STDs all of which were closely linked to the issue of women's health.

She pointed out that there was a close nexus between women's STDs and RTIs and vulnerability to HIV/AIDS infection. In fact, several of the women's RTIs were not necessarily sexually transmitted, but are caused by poor living conditions and malnutrition. The physiology of women, in which the reproductive tract had a wider area of mucous membrane was located deep within the body. The more delicate nature of the tissue made it more vulnerable to infection, tears and lesions making it much easier for the HIV virus to enter the blood stream directly. Another key reason for the greater vulnerability of women to infection is their general handicap in not being able to negotiate for safer-sex practices. Unprotected sex is the single largest risk factor in transmission of HIV to women.

Further, she pointed out that women suffered from multiple RTIs, the ill effects of abortion, chronic pelvic inflammation, frequent pregnancies, premature and forced sexual intercourse, and trauma to their internal organs. Thus, she said, it was imperative that a 'reproductive health approach be taken rather than just the STDs' approach presently being followed by the government. Questioning the validity and efficacy of the approach, she said that a counsellor should be located in the gynecology department of hospitals rather than in the STD clinic of the hospitals, who would then refer women to the STD clinic.

The idea of risk is a difficult concept to convey, especially in AIDS education. Those campaigns which ask the women to 'just say no' or to insist on condom use fail to recognise the reality of women's lives: such actions are more likely than anything, to cause the loss of economic and emotional stability in their closest man-woman relationships.

Touching upon the feminist critique of the representation of HIV/AIDS, she said that while the feminists spoke of reproductive rights, including the right to abort, to information, contraceptive services etc., they had very little to say about the core issue of women's reproductive health. She quoted statistics to say that while the prevalence of STDs in women was 13. 1% nationwide, a UNICEF Survey in 90-91 said that it ranged from 5% in certain states- Jammu and Kashmir, Tamil Nadu, Maharashtra and Andhra Pradesh, upto 20% in other states. Another micro-level survey by health activists, Doctors Rani and Abhay Bang of 700 women in Gadchiroli, a backward area of Maharashtra over a two-year period revealed that

over 80% of the women suffered STDs, pelvic inflammatory diseases (PID), and cervicitis. Almost all women had white discharges. These diseases were so prevalent that the women thought them a perfectly normal part of being a woman, 80% felt that there was no need for treatment. The other side of the issue was, even where there was a doctor who was available, the women did not mention these diseases

a) For fear of stigma;
b) They felt that the doctor should ask them about their disease rather than they raising the issue themselves.

On the criticism that the promotion of condoms put the control in the hands of the male, she said that while it was true that condoms were considered a male method, it need not necessarily be linked to empowerment of women in the sexual relationship. She illustrated this by exploding the myth that women, especially sex workers dependent upon income from male clientele, were unable to negotiate condom use. Her experience of over six years with SIAAP with this group of women had amply proved that this was perfectly possible. She admitted that however the same may not hold good for urban middle class women who may actually have less negotiating power despite economic and educational advantage over sex workers.

Shyamala next pinpointed other aspects of HIV and women. She spoke of HIV related violence against women, relating specific instances of how people of a village tried to burn alive a girl who they came to know was HIV+; another incident related to a village who tonsured and hounded out a few sex workers living in that village. What caused concern was that the villagers reacted in this way following an AIDS awareness camp held by an NGO.

She spoke briefly about the law relating to prostitution in the country; the salient points being:

a) Soliciting is not illegal. However trafficking or profiting from prostitution is illegal. However, what usually happened was that sex workers were regularly harassed, while the brothel keepers and pimps went scot-free;
b) Soliciting in a public place was banned. However, the definition of 'soliciting' is so broad that any woman standing in a public place such as a bus stop or just walking along the road could actually be arrested for soliciting.

Another aspect of the HIV/AIDS issue was the human angle. While marriages were still arranged according to convention, it was difficult for the bride's family to insist upon assurances that the groom was free from HIV infection. She related a case where a HIV+ couple, in which the wife, only 23 years old, was abandoned by husband and in-laws a few

years after marriage, because the husband started displaying symptoms of AIDS. The in-laws spread the news that the husband had caught the "disease" from the girl after marriage. The girl, of course, is now HIV+, having been infected by her husband.

The session then was thrown open for questions. The first one related to the issue of condoms being projected as a fail-safe method. In response, Shyamala said that condom use should be put into perspective. Safe-sex practices did not mean just condom use but also included abstinence, monogamy, non-protective sex, and the prevention and treatment of STDs. She affirmed, however, that condoms renamed the only known way to prevent re-infection.

Sanjay, a participant asked whether there was any legal recourse to protect the rights of the spouses of HIV+ persons. Shyamala asked X to respond, and she responded that the spouse should not be kept in the dark but most be told. Raja added that there was legal responses which had been used. Manisha selected a case of a 19 year old girl married into a family where incest was a way of life. She approached a local NGO for help and they were able to take the necessary legal steps to release her from the marriage. In this case, the parents of the girl were very supportive and fully co-operated to help their daughter.

Raja requested Shyamala to say a few words on sex workers and how they were now able to insists on condom use. Shyamala responded by observing that one of the most remarkable developments was that the sex workers reported less violence by clients. Somehow, being able to negotiate with clients seemed to give them a better standing with them. While on the one hand the media and the establishment failed to recognise the ability of the sex workers to negotiate, the training enabled the women by,

a. Reinforcing self-esteem;
b. Building capacity to strategise in negotiation;
c. Enabling condom use in upto 70% cases in 6 months.

After this, collectivisation of the sex workers enabled them to use condoms in 100% of the cases. Shyamala also shared the experience of the meeting that the sex workers from South India had with the Chairperson of the National Commission on Women in Chennai a few weeks before. She said that the women showed remarkable clarity and boldness in identifying their needs and problems and in setting them forth to the Commission. Dr. N.H. Antia intervened to observe that often political developments had their impact on public health status of populations. Citing the case of China, he said that STDs had been almost eradicated there by the political revolution which also brought in radical social change. He expressed the hope that

a salutary change may occur if the Panchayati Raj systems take firm root among the rural populations of our country, and once they are empowered to take over the effective administration of their villages.

Cynthia raised the question of the health needs of women being viewed by the health system purely as reproductive or rather birth control services for women. Responding, Shyamala said that more on this aspect would be dealt with in the following session. However, she said that women often cannot protect themselves from infections due to living conditions and social norms. They also lacked the political and social status to insist on better infrastructural facilities such as water, sanitation and health care systems. One method of countering this was to train more local based field level health workers as the first line health service. This cadre could then link up with government services and play a liaison and even a confrontational role with the official health system.

Dr. Thomas remarked that one area opening up was the home-based care of HIV/AIDS patients. While this seemed a very viable and positive development, what it really meant that the task of care-giving was put upon the women who ended up confined to the home, caring for the gravely ill men, often at very great risk of contacting the infection themselves due to handling the body fluids of the sick person.

Shubha made the observation that the link between AIDS and sexuality made it difficult for many people to speak openly about it, free from cultural constraints. Taking up from this remark Manisha shared the results of a survey of 200 women from upper middle class families on contraceptive use. It was found that they faced real constraints in adopting contraception. Dr. Antia reported that in the field area where he worked, the women, while talking about their reproductive roles, expressed that they did not even know what their bodies looked like! However, with appropriate information and training, it was found that these same people can help themselves to meet 80% of their own health needs. Shyamala added that as part of their training, the women at SIAAP were trained in self-examination, to diagnose simple infections and assess the nature of the discharges. This gave them a sense of self-confidence and demystified many of their illnesses.

Dr. Raghuram remarked on the patriarchal system and its ruthless exploitation of women's needs denying them access to the resources of Community Care. The government abdicated its responsibility in providing water, sanitation, health care etc. Far worse, it was often responsible for human rights violations such as incarceration of HIV+ persons. Reacting to these remarks, Shyamala said that community care seemed much more a feature of life in the African continent than

in India. "I really do not know to what extent this will work in India" she said. In response to the issue of Human Rights, she said that the only way to remedy the violations was to take up a number of court cases so that precedents could be set and norms established in the way HIV+ persons were dealt with.

Venugopal wondered aloud as to whether these questions should be viewed as civil rights issues or as problems in search of solutions. John remarked that more would be said on the subject during the next session, as it was a wider question. He also pointed out that the question of whether one should breach confidentiality in revealing the HIV+ status of the person to the spouse or partner assumed a political nature.

Raja brought to the notice of the group the fact that NACO's spots on TV, supposedly on AIDS awareness, actually depicted women as the source of HIV infection, further reinforcing harmful gender stereotypes. The session was brought to a close by Aarthi Pai who summarised briefly the various points brought out by the resource persons and others who raised issues during the discussions.

Session 2 : HIV/AIDS as a Development Issue
Chairperson : Dr. Shobha Raghuram
Resource Person : Dr. N.H. Antia

Introducing the speaker, the Chairperson said that Dr. Antia was a plastic surgeon by profession and a community health practitioner by choice. He had also founded the Foundation for Research in Community Health. Based on the firm belief that health was an issue of the well-being of the community, she said that he specialised in review and critique of health care budgets, the role of the State, the World Bank and the impact of the Structural Adjustment programme on the health of communities. His work focuses on the health system in Post-Independent India, and is founded on the premise that Health is a fundamental Right.

Dr. Antia's presentation placed the issue of public health problems in general in the broad politic-economic context of the country. Observing that "Medicine is social science and Politics is Medical Science on a large scale", he continued that health was largely determined by social conditions, and this is seen chiefly in its failure which brings on illness. Hence, it is incorrect to look at the medical profession for health needs.

In a quick overview of how the government's health system has functioned over the years, he said that in the early years after Independence there was a fairly good system in place which

gradually began to lose its responsiveness to the people's needs by a combination of apathy, government policy and skewed priorities. In 1981, the J.P. Nayar report and the ICSR & ICSSR Report were submitted to the government, on the topic Health Plan for the nation. These reports stressed the need for focus on meeting basic needs of the population - water, nutrition and sanitation. However, these reports have not been accepted or implemented, paving the way for health care to be turned into "failure of health," to illness, to a business.

Dr. Antia cited the success stories of UK and China, both very different in their own ways. In the UK, the Labour Government which took over there after the War, implemented into the contents of the Beverage Report. This plan became the basis of the National Health Service, which went on to become one of the most successful government-run public health programmes. In China, the policy was imposed from above by the Maoist regime but as the implementation was by the people, it was able to meet the needs of the people quite effectively.

India, he said differed in three important ways from both China and UK, and he proceeded to cite examples. The first important difference was that in India, universal franchise was given to every citizen, man and woman, as a matter of course without any major political upheaval on that count. Second, India consisted of two distinct socio-economic political entities - 'India' and 'Bharat'. These two groups lived side by side without really knowing each other. 'India' is also cynical about 'Bharat', and about the reasons for Bharat being poor, illiterate and "uninformed." The third way in which India is a different country was that the Army has shown no inclination at all to interfere in the political life of the country.

In India, in contrast to UK and China, the trend has moved towards the 'medicalisation' of health, with the overproduction of doctors and drugs and medicare which is more on the western model, based on the wrong kind of values, he felt. For instance, pain was a constant companion for the poor in the country. They could cope with and live with it, whereas the important impact was felt in their lives when their capacity for labour and hence income generation capacity, is impaired due to health problems. He pointed out that the poorest families still spent 80% of their income on food. But these same families also spent 8% of their incomes on 'injections' when sought medical help.This actually contributed a lower nutritional status. These were the results of a survey conducted in three districts in Dr. Antia's field area.

Outlining the health scenario in the country, he made the observation that it is commonly felt that there was no money for health in our country. In fact, he said that India was among the highest spenders on the health sector in the world in terms of percentage of GDP. Thus, it was not a matter of 'no money', but rather an issue of 'no application of brain'. The Bhore

Committee report laid out a blueprint for health involving the people. The Report, though accepted, was not implemented due to the collusion of medical professionals and bureaucrats. Therefore, we have a public sector health system which does not work, is accountable to none and an expensive exploitative private sector health system in which the tendency was to:

(a) distance yourself from the patient and
(b) withhold information;

thus mystifying medical science and making it the domain of those who had the "knowledge." Further, Dr. Antia said that there was a vast rural-urban divide in expenditure on health - in rural areas Rs. 30 was spent per capita while it was Rs.100 per capita in urban areas. China only spent 3.5 percent of its GDP on health, two-thirds of it in the public sector; in India 75% of the health expenses lay in the private sector.

The real health problem in our country is poverty, he asserted. Our masses are undernourished and ill because nobody has still discovered a vaccine against poverty.

The answer to the need lay not in "illness care" as is the present orientation of the system, but rather in preservation of holistic health and the prevention of major diseases. He said that he had been involved in a grassroot's health initiative, where the health needs of the several thousand population in a rural area were met at a cost of just Rs.7 per capita, including prevention and treatment of tuberculosis, leprosy, gastroenteritis etc. This would be possible on a wide scale only if we are willing to exchange our knowledge with the age-old, holistic wisdom of the masses. Another constraint is the fact that we are unable to convey this wisdom in a holistic manner. Knowledge is a matter of organising ourselves and sharing information. But because we have not done this well, the killer diseases, which were receding a couple of decades ago are coming back - malaria, plague, tuberculosis and gastroenteritis. We are now being given loans by the World Bank to help tackle these diseases.

Referring to the issues of HIV/AIDS in public health, he said that it was the way leprosy used to be till the fifties; patients suffering from leprosy suffered severe social stigma. There was no known cure down the centuries till the fifties and the disease came on gradually. Hospitals also refused to admit or treat leprosy patients on par with others. Dr. Antia said HIV/AIDS was almost a bogey or a myth in terms of the hype that accompanied all writing and discussion on HIV/AIDS. Research into AIDS vaccine and treatment was like the discovery of the hepatitis vaccine which costs Rs.750 per dose - out of reach of the very people who needed it most, because hepatitis affected those who could not afford access to safe portable water. In fact, Dr.

Antia asserted that the WHO was raising a hue and cry about HIV/AIDS mainly because it posed a threat to the West. He said this kind of high voltage campaign could backfire because it would send persons with HIV/AIDS underground. The only way to counter such hype would be to use regional language newspapers to carry balanced articles and circulate pamphlets by credible social workers such as Anne Hezare. HIV/AIDS was a sort of litmus test to identify the responsiveness and effectiveness of health systems, said Dr. Antia. Instead of focusing on HIV/AIDS as an illness, there was a need to emphasize the sexual health of people. Service provision in this area was more important rather than just information. NGOs have an important role to play. More NGOs are needed to play a role at the community level. The value base of medical education needs to be addressed. The legal machinery has to be conscientised on the issue and geared up to meet the needs of HIV/AIDS affected persons' sensitively. The work culture in governments and NGOs need to be changed and an assertion of political will has to occur.

In the discussion that followed, the first question asked was about the unresponsiveness of the system to the needs of the people. Dr.Antia said that often the one point response to any demand for government services was the transfer of money to administrative departments. However, this money tended to stay there, often at the district level. He said the solution lay in redistributing not just money but also other resources in to the village level, not just to districts, taluks or panchayats. Spending decisions should devolve to the locals and financial control handed over to the Community. Another participant observed that in Orissa, Rs.600 crores were allotted for development and the social sector , but the lack of political will had made it impossible to utilise the funds effectively. Dr. Antia remarked that according to a survey conducted, Rs.2.5 crores had been allocated for development to one panchayat with a 25,000 population, but the local people had never even heard of it, let alone enjoyed the benefits of it. He said that another feature was that in a sense the NGOs were more dangerous than the government because they were credible and created dependency. This was harmful for the development of the local populations into citizens willing to take responsibility for their own lives.

John added that the huge allocations being made by World Bank on AIDS would further indebt our society. Leslie tended to agree, saying that the AIDS "bogey" has sidetracked attention from other equally serious and persistent problems though he added that he did not wish to underplay the seriousness of the AIDS situation. Joe Thomas interjected that he certainly felt that AIDS was no bogey. During his work at Meghalaya, with the AIDS affected population there, he had attended the funerals of over one hundred young people, all friends and personally known to him. Therefore, social negotiation was necessary to focus optimum action

and resources in an appropriate manner, he asserted.

Shyamala responded to the foregoing discussion with a few well thought out points. She said the balance needed to be restored in the whole approach to the AIDS issue. This could be done, according to her, by:

- Focusing on sexual health rather than AIDS;
- Breakdown barriers to the dissemination of information on sexual matters;
- Set up benchmarks for vulnerability. Assuming an infectivity rate of 5 percent in a population of 900 million and assuming a 100 million dollar fund for AIDS over a five year period, it boiled down to 4 dollars per person for five years. Any calculation would show this was far too small a sum the costs of prevention, treatment and rehabilitation needed for the AIDS issue. Some of the biggest items of expenditure, however, tended to be on importing experts from WHO, which cuts into the actual amount available to the affected population.
- An information approach not backed by services is practically useless, but at present far too much was spent on information and far too little on services.
- She had first hand experience in running field based interventions on AIDS and had found that it was possible to reach between 400-500 sex workers or a population of 2000-5000 people with a fund of Rs.30,000/- per annum. Thus, the most practical need is for a community-based approach using a member of the community as the key person.
- Naive doomsday predictions being made as any disease ran a mutual course, starting slowly building up momentum, peaking and then hitting a plateau and finally tapering off.
- The government health services were presently inadequate and the staff of the PHCs needed to be able to tackle the AIDS issue rather than the larger hospitals.

The post-lunch session opened with the Chair inviting Venugopal who had raised a point just before lunch to do so at this point. Venugopal spoke of the present network of PHC → Taluk → District and General Hospitals. But the very foundation of the system - the PHCs - just do not function at all. How could one make it work? Admitted that NGOs and Gandhian Institutions have a role to play in promoting a people's movement and strengthening the role of the Panchayati Raj systems, is this still enough? This was Venugopal's query.

Dr. Antia while broadly agreeing with the analysis, felt that too often people felt the need to

pressurise the government to do its role. According to him, it was the easiest thing to give the technical and managerial role to the government and expect them to do the job, but its vertical, top down approach was the opposite of people's power. The only reason things do not work well at the field level is the problem of poverty - for which a vaccine had yet to be found !

Dr. Antia proposed a totally new classification of diseases - instead of going by the nature and pathology of the disease, the diseases should be classified according to the skill and knowledge required to manage it. This would remove the glamour attached to the technology and focus on low-tech practical options for people's health. He cited the case of the system devised in the Munnar Tea Estate where 10,000 tea picker families lived in the remote area. The teapickers were themselves included in the training programmes and an effective network of health services including referral for major diseases to the General Hospitals was being seen at a cost of just Rs.120 per capita per annum in 1990. Thus, it was certainly possible for an empowered population to run its own services. Cynthia then asked for Dr. Antia's comments on the nature of the medical education system being followed in the country. Its value base seemed far from what was necessary in the Indian context.

Dr. Antia said that this was all part of the situation in India, which was complicated by many factors. For instance, India had no less than 70,000 drugs and 20,000 ayurvedic drugs. This skewed system of priorities, where essential drugs were fast going out of reach of the purse of the common people and the drug and technology based treatment doled out by the expensively trained doctors was the bane of India's health problems. He cited the case of the U.S where 1 trillion dollar was spent on the last six weeks of terminally ill patients. Even here, 45 million people have no access to health care they can afford due to high costs.

Mathew, reacting to this, shared the experience of training tribal youths, from a remote hill area in Maharashtra called Patan in basic health skills. The quality of life of the tribals immediately showed a rise as they stopped travelling 3-4 hours spending over Rs.100 per trip for simple stomach disorders and deficiency disorders. This actually caused doctors from the plain areas to go scouting to the hills to find out why the bulk of their patients - tribals - had suddenly stopped travelling down to the plains for seeking their services. This was a successful experiment in the empowerment of local communities to meet their own health needs according to him. The trained youth also earned small sums from their services to their fellow tribals. Another example of how, media also played a role in 'invisibility' the struggle of the people was shared. In Chiplun, a backward area, a factory was started which quickly caused health problems for the local population due to pollution. The government's response was to start a hospital. The media reported the inauguration of the hospital, but blanked out the

agitation of the people for access to clean non-polluted water held right at the venue.

Dr. Antia commented that the people of India now needed to take up the "third war of Independence" against the forces that continued to ignore their rightful claims to resources, information, education and dignity.

In wrapping up the session, Shobha Raghuram said that Dr. Antia's analogy of the doctors' knowledge vs. the people's wisdom was an excellent one to describe the situation not only in the field of HIV/AIDS but in our society's response to people's needs. She summarised out a few credos which would help us to understand the nature of the problem :

i. Doctors and the medical establishments are not pro health but pro illness' (a vested interest in illness);
ii. Inequitable conditions are a cause of ill health;
iii. The need of the hour is a bottoms up approach;
iv. Illness has now to be understood as an industry, a business that is fuelling the overproduction of doctors and drugs of the most inappropriate kind;
v. The value systems being practiced are causing a deculturation of our people. "technologies" and the control of knowledge now characterises the medical profession and the bureacracy. It is now a case of wisdom vs money;
vi. We are fast turning from being need-based communities to a greed-based communities;
vii. The rural-urban divide in health allocations continues with the urban populations getting Rs. 100 per capita per annum against Rs. 30 in the rural areas;
viii. Vested interests continued to distort the priorities of human problems;
ix. There is a need to demand accountability from the system.

Outlining the situation in the area of HIV/AIDS and Development, she said that it was characterised by a lack of community support, scarce resources, an inflexible medical bureaucracy, and, a total lack of preventive work in this area with almost no palliative care for the affected persons. A dogmatic and biased understanding of the nature of the issue and a male-gendered approach was also a barrier to seeking solutions. There was a need for contextualising the problem by setting it in the social context of poverty, unemployment and gender, caste and class discrimination and conflict. The needs of vast populations were not being met. NGOs and government were the two key players in the area of HIV/AIDS and Development.

Shobha also said that there had to be an effort for groups to work together in the area of health HIV/AIDS, health care and development. These approaches had to be secured at the community level by an injection of political will, harnessing community support, strengthening the functioning at PHC level through devolving financial responsibility and accountability to Panchayati Raj institutions. Equity and justice had to be uncompromising normative values in such a scenario.These steps would ensure the sustainability and responsiveness of the system not only to HIV/AIDS issues but to the wider issue of development. "There can be no technical fixes to people's problems," she asserted. Therefore, services in counselling, training and resources and political lobbying for human rights violations were necessary to continue to meet the needs in these areas.

Session 3 : HIV/AIDS and the Role of the Media
Facilitator : John D'Souza

Rather than a presentation by a resource person, the session was more of a brainstorming session.

The group discussed the role played by media in the issue. There was a constant tension that existed between the economics of media and media ethics, the group agreed. As the issue of HIV/AIDS was primarily associated with sexual behaviour, it lent itself rather easily to sensational, inaccurate and often damaging media coverage which generated fear, excessive attention causing great over exposure.

Was there a role for NGOs and concerned citizens, was the question. This was discussed and the group agreed that two areas could be taken up :

i. Advocacy on HIV/AIDS;
ii. Attempts to sensitize the media on the need for the right kind of media coverage for such a delicate issue.

Comparing the role of Mass media with NGO publications, it was felt that the mass media scored in the areas of scope, readability and news value. While NGO newsletters were often good on content, they were not too good at dissemination. Their readership was limited and they often ended up "preaching to the converted.". The plus points were, however, that NGOs reach a concerned set of citizens who are aware and active in society. The newsletters are useful for information discussions, decisions and action. As they reached field level activists, it was important to keep in mind the literacy level, language, means of cultural expression, etc.,

when writing for newsletters. Often, the person involved at the field was not the one wanting the newsletter and this makes a difference to the depiction of field realities.

The question of whether an "alternate media" could be promoted was discussed. A shared approach among NGOs involved in media/communication would be beneficial, it was felt. Production values should be kept high to promote reader interest. Financial sustainability is a real issue as most persons are unwilling to pay for newsletters from friends and associates. It was very important to keep the 'target audience' and the purpose of the communication in mind at all times to make newsletter relevant, it was agreed.

The topic was then guided to an exploration of principles to be followed in Communications in general and on HIV/AIDS in particular.

A great deal of heated discussion was generated when general principles were sought to be arrived at in dealing with HIV/AIDS issues. Finally, the following was agreed upon. Coverage, especially by NGO's publications should ideally:

- Be non-discriminatory;
- Be gender sensitive;
- Be non-stigmatising;
- Be oriented to practical issues;
- Maintain confidentiality and give the affected person the right of informed consent;
- Give the right of refutation;
- Be need-based.

There was a debate on whether these principles could be applied as hard-fast rules. While one section felt that this should be the case another group felt that they were left to each individual to interpret and apply as relevant in his/her own situation. There was no consensus, with some persons subscribing strongly to the latter view.

Shyamala made an open offer for training and financial support for one person from an NGO for a year who could then specialise in writing on HIV/AIDS related issues. YUVA, an NGO and Cynthia expressed an interest in this offer. Participants then shared what they were willing to contribute to a joint programme of Action in HIV/AIDS area. Some of the possibilities discussed were :

- A centralised clearing house of information to reach NGOs to which groups like Chetna, Indian Health Organisation, Women's Feature Service and CED were willing to contribute time and resources.
- A participant from MASSES in Andhra Pradesh offered to translates articles on HIV/AIDS in Telugu and offer them to Telugu NGO publications as a news service. Raja offered to support this initiative.

Other ideas included :

- A story competition on ethical problems on HIV/AIDS. A Joint Column, syndicated to mainstream media (PRIA, ACHAN, Change makers expressed interest in being involved in this activity);
- Evolving cartoons on HIV/AIDs issues - (Astha, Charkha and ICRA had already done some work with cartoons);
- An exchange for poster ideas;
- Audio media - songs, slogans, audio tapes, radio spots;
- Alternate media based on oral culture to reach the grassroots ("Bharat" had its own idioms, vouching and cultural expression). Rural NGOs could supply material as stringers to mainstream media.
- Internet, conferences and the Home Page could also be used by NGOs for building up campaigns. These could be taken up at a later workshop.

For the rest of the five-day workshop the participants shifted the focus from HIV/AIDS and went on to NGO media, newsletters, documentation etc. The following commitments and follow up actions were made.

(a) A network or forum to help NGO newsletter editors/publishers was proposed and agreed upon and PRIA offered to host the next meeting around September 1996;

(b) A profile survey of NGO Newsletters would be relevant to assess the human and material resources that were being put into these efforts, it was felt. PRIA would coordinate this effort, with others like MASSES, Changemakers, Adhikar and YUVA helping out;

(c) CED would take on the responsibility of holding the training in electronic communications if PRIA or CHETNA could be hosts.

(d) CED and CHETNA would put together the report of the last day, which would then be circulated to as many NGO newsletters as possible. The next meeting of NGO newsletters could then be organised, possibly including some training.

In informal discussions, participants said that they had really learnt a good deal about what HIV/AIDS issues and were able to relate to it better, especially after meeting HIV+ people.

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Appendix

WORKING PAPER 'Hivos AND AIDS'

Humanistic Institute for Co-operation with Developing Countries (Hivos), The Hague- The Netherlands

1. THE AIDS PROBLEM

In the early 1980s the world was startled by the sudden emergence of the HIV virus and its subsequent fatal disease AIDS. Initially those phenomena still seemed restricted to the United States and Europe, but is soon appeared that HIV and AIDS existed elsewhere at an even larger scale (like in Africa). Meanwhile it has become more and more clear that the developing countries are (and will be) paying the highest toll. According to recent estimates from the UN-World Health Organisation (WHO) approximately 90% of the number of people with HIV and AIDS will be represented by people living in countries of the South.

1.1 The gravity of the AIDS problem in the South

As there is a lack reliable statistic evidence, the number of people with HIV and AIDS can only be assessed approximately. Appendix I gives a summary review of recently presented estimates.

From those estimates (from, amongst other, the WHO) it becomes clear that the most alarming situation of this moment exists in Africa. Both Latin America and Asia are - generally spoken- in the early phase of the scenario which Africa has already passed through. It has been estimated, however, that in the near future Asia will be facing an explosive growth of the number of people with HIV and AIDS. The WHO predicts that in the middle of the 1990s or at the turn of the century more Asians than Africans will be infected annually.

In Africa the spread of HIV and AIDS has taken disquieting shape, particularly in Sub-Saharan Africa. Especially Uganda, Tanzania and Kenya have an extremely high contamination rate. In Uganda, for instance, 22 thousand people with AIDS have already been diagnosed and the number of seropositives has been estimated at 1.3 million. Under the current circumstances this number will be doubled every half a year.

Asia is one of the regions where people with HIV and AIDS are highly exceptional according to the official statistics and where the AIDS problem is as such mostly denied internally. Yet this systematic negation is concealing a worrisome growth. Some countries in South East Asia, like Thailand and the Philippines, distinguish themselves by dealing with the issue openly.

In Latin America the diagnosed people with HIV and AIDS initially remained restricted to specific groups of society. However, HIV and AIDS are spreading more and more outside those groups, especially in urban conglomerates. The situation in the Caribbean, on the other hand, is comparable to the one in Africa. In a country like Haiti a relatively large number of people have been infected (in the middle of 1991 approximately three thousand seropositives in five million inhabitants) and the contamination has not remained to specific groups. The largest numbers of people with HIV and AIDS in Latin America have been assessed in Brazil and Mexico.

Until recently the spread of HIV and AIDS in the United States, Europe, Australia and Latin America remained mostly restricted to specific groups, such as men with homosexual contacts and intravenous drug users. Particularly in the north and south of America the virus is gradually spreading out side of those groups. With this development the problem in those regions is growing towards the situation in

parts of Sub-Saharan Africa, where the AIDS drama has struck all categories of the population. Especially because of social circumstances this has particularly negative consequences for women (see paragraph 1.2).

The continental differences are therefore not only connected to the numbers of victims, but are also directly related to so-called 'high-risk' groups- A well-considered AIDS policy will therefore have to be adjusted to those differences and also differentiated in its implementation.

For that matter, HIVOS is aware of the controversial character of the term 'high-risk groups'. It could cause stigmatisation and (further) marginalisation of certain groups in society (including sex workers and homo-bisexuals).

1.2 The consequences at demographic, social and economic level.

The consequences of the AIDS problem are far-reaching, both on international and national level. Of course this is particularly true for Sub-Saharan Africa. At demographic level one could speak of a very extensive contamination with HIV and (in the near future) a large number of deaths, even though these deaths, even diseases as a result of reduced immunity though HIV infection. The contamination is particularly spreading among the population group in the ages between 15 and 45. Thus the generation gap is developing in the literal sense.

Precisely this generation consists for the most part of labour force and furthermore of those people who are at the peak of their productive lives. Therefore AIDS also has far-reaching economic consequences. This is certainly not only the case on a national level, where the active labour force disappears from the production process. Also within individual families it is not exceptional that the breadwinners are literally eliminated through contamination.

As a consequence the extended family structure, as is generally known in Africa, become seriously disrupted. This phenomenon, in combination with the death of many parents, leads to a serious orphan problem. The social disruption, however, does not remain restricted to those aspects. The people with HIV and AIDS as well as the alleged high-risk groups are in danger of becoming marginalised even further. Not seldom this also involves serious violations of human rights, often also systematically. Examples are discrimination of people with AIDS involving medical treatment, the compulsory AIDS tests for the alleged high-risk groups (this happens, for instance, in Latin America) , the loss of employment and housing when one is seropositive, travel restrictions for the infected, expulsion from families and communities of people with HIV and AIDS (sometimes even permitted by the government because of the absence of protective measures) and even isolation of seropositives by the authorities, either at home or in detention centres. Examples this last violation are known to exist in, for example, Cuba and some federal states of India.

The government is primarily responsible for taking adequate measure. The quality of those measures is in practice often insufficient. To tackle the AIDS problem effectively it is essential to break the taboo on sexuality. The contamination with HIV is after all mostly caused by sexual behaviour, while in most countries there is still a taboo on the discussion of sexuality. In order to establish an effective policy on AIDS prevention it will therefore be essential to make sexuality debatable and here the national authorities will have to play an active part. Unfortunately, however, this is still not happening sufficiently.

The circumstances described above are to a large extent related to the situation in the areas that are affected the most. Some aspects are therefore specific elements within African context. The disruption of the extended family structure and the orphan problem play a less important part in Asia and Latin America.

It appears that in several aspects women suffer more from the consequences of HIV and AIDS than men do. As a result of the existing balance of power between the sexes women are generally less capable of protecting themselves against the risk of becoming infected women, as opposed to the number of seropositive men, is considerably higher in the South than it is in the North. In addition women are not seldom maneuvered into a position where they have to combine the caretaking of their ill family members with their role as breadwinner. On the one hand this is a result of the high strain on the existing health facilities and on the other of the established family structure being disrupted.

Neither children escape the consequences of HIV and AIDS. The orphan problem has already been mentioned before. Pregnant women who are infected also pass the virus on to their unborn children, which to a large extent counteracts the progress so far made over the last decades in the combat against child mortality.

Finally it has become apparent that in certain areas HIV is spreading very quickly among children. This seems to be the result of an evident trend of sexual contacts of adults with very young children.

2. POLICY CHOICES OF HIVOS INVOLVING THE AIDS PROBLEM IN THE SOUTH

2.1 Objectives

As a humanistic development organisation HIVOS-the Humanistic Institute for Co-operation with Developing Countries - feels a particular responsibility with reference to the earlier mentioned taboos on sexuality. Values and standards on this particular subject are often being perpetuated through religion and related dogmatic opinions and attitudes respectively. For instance, by holding on to 'proper customs' and rejecting 'immoral practices' the prevention of AIDS is seriously impeded and taboos on sexuality are upheld. Significant examples are reducing the discussion of AIDS and sexuality to a matter of 'marital vows' and the rejection of distribution or usage of condoms. It is highly essential to break these patterns. It is therefore of crucial importance to support those organisations and activities that are not restricted by such dogmas and that are therefore capable of promoting the debatability of sexuality, also with reference to AIDS.

The secular and undogmatic character of Hivos and its network of counterparts offers an existing possibility to actually interact from the mentioned perspective with respect to the relation between AIDS and sexuality. As a development organisation HIVOS cannot ignore the AIDS problem either. After all, the spread of AIDS in the South is related to the poverty problem of this part of the world. It is not coincidental that often the same groups of the population are affected both by poverty and HIV or AIDS as well. In their marginalised position those population groups have generally insufficient or no access to the AIDS prevention channels.

Information often does not reach this population group, either because it is presented in written form or because spoken information is given on radio and TV. There is also a general shortage of preventive means (such as condoms). As a

consequence the ignorance involving AIDS prevention is upheld and those people are at high risk of getting infected with HIV.

Regarding the nature, (the potential) scale and the consequences of the AIDS problem in the South it can be said beyond doubt that AIDS prevention is an essential precondition for development. Without such efforts development aid cannot be sufficiently sensible or effective.

Against this background HIVOS distinguishes three objectives.

Firstly it wants to enable non-governmental organisations in the South to enforce the development and execution of AIDS prevention strategies by their governments. If the governments in question fail to do this, either through incapacity of through unwillingness, it will be evident that the counterparts themselves will have to develop and execute preventive strategies or have them developed and executed.

The second objective is aimed at the protection of human rights with respect to (future) people with AIDS. This includes, for example, the combat against discriminating measures towards so-called 'high-risk groups', people with HIV and AIDS, but also pleading for access for those groups to the most elementary human rights and to facilities like employment, medical care and housing.

A third objective aims at the enforcement of emancipation processes in society with relation to AIDS and sexuality. This applies to, amongst other, the human rights position of women. It is of great importance that the breaking of taboos concerning sexuality will be connected with the improvement of the legal position of women. As a result the existing imbalance of power within family and society will be brought up for discussion.

2.2 Target groups

Because of the direct relation between the AIDS issue and the poverty problem the target group in principal consists of that specific part of the population, that HIVOS mostly works with and for whose benefit the organisation generally exerts itself. Briefly and generally speaking this involves the poor urban and country population, who have no access to the most elementary facilities and who therefore represent an important high-risk group with respect to contamination with HIV.

Within this wide range Hivos makes itself particularly approachable for alleged high-risk groups. One aims at homo- and bisexuals and sex workers., who, because of AIDS, are more than ever exposed to stigmatisation because of their sexual nature or behaviour. Considering the fact that also many women are being affected by the consequences of AIDS (see paragraph 1.2), and that Hivos in addition regards the issues of 'women and development' as an integrated part of its general policy, it is obvious that women in this respect should be given specific attention.

The reality in the different developing countries also shows that (labour) emigrants, refugees and prisoners are more in danger of getting infected with HIV. They also represent a special target group for Hivos.

Obviously the choices of Hivos in this matter are highly dependent on the gravity of the situation (the size of the problem and the composition of the 'high-risk groups'), the local circumstances and the (latent) presence of social institutes,

that are able to function as counterparts of HIVOS providing they look after the interests of the target group in an institutional manner. This is where differentiation will be essential.

3. POLICY IMPLEMENTATION

3.1 Activities

Keywords with respect to the implementation of the HIVOS AIDS Policy are prevention, promotion/protection of human rights and network development, as indicated below.

Information, training and education play an important part in the prevention of AIDS. Information facilities for AIDS prevention can, for instance, take place through radio programmes, educational theatre shows and through illustrated brochures, whether or not in their own language or dialect. Along those channels target groups are not only being informed and alerted, the NGOs are also contributing actively to making AIDS debatable.

The promotion of interests is directed towards seropositives and people with AIDS on the one hand and to the alleged high-risk groups on the other. This involves, for instance, safeguarding primary facilities as regards health and medical treatment. Furthermore the equal position of both target groups will be secured. The provisions for human rights protection as implied above can be realised through activities such as lobbying, research and publication of the results and giving publicity to violations.

A third category is aimed at organisation building. Within this context HIVOS attaches great value to network development through which collaboration among different NGOs will be promoted in various fields. By introducing newly established or to be established groups to already existing information networks, the former can be provided with devices to develop and implement strategies independently. In this combining of forces HIVOS can perform a bridging function.

3.2 The role of the NGOs

The combat against AIDS is primarily a task of the authorities. However, for the realisation of that combat participation of non-governmental institutions is of great importance.

In situation in which the government has already indicated to be prepared to tackle the AIDS problem seriously, the interference of the NGOs will mostly be of a complementary nature. This means that they will support prevention projects and programme which are not financed sufficiently by their own national authorities of where those authorities are seriously hampered by, for example, conservative groups in society.

In cases in which the government fails or neglects its responsibilities completely, it will be even more urgent that the NGOs recognise their share in the combat against AIDS. The non-governmental organizations will have to exact necessary provisions from their government with even more emphasis. In the extreme case they will -where possible- have to take their own initiative for such activities.

COMMUNITY HEALTH
LIBRARY
AND
INFORMATION
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As regards the debatability of sexuality and the emancipatory effects to which it is expected to lead the NGOs can (and must) play a structural (vanguard)part.

3.3 The role of Hivos

The setting of tasks by HIVOS is first of all aimed at confining the potential to those NGOs in the South, who are approachable for the subject of HIV/AIDS proceeding from the objectives as defined by HIVOS. Regarding already established relations with counterparts of HIVOS the latter directs its efforts towards getting the HIV/AIDS issue on the agenda of those organisation.

Groups in the South that have to be formed or already have been formed as a result of HIV/AIDS will receive direct support from HIVOS to establish the necessary organisation structure. In addition HIVOS makes a great effort to strongly support initiatives with respect to coordination and network development (nationally/internationally). Only later on it will be possible to give a definition of the targets regarding the scale at which HIVOS is going to contribute, which will be expressed in money and collaboration agreements.

The situations of the countries where Hivos is active are unequal and will first have to be defined more clearly.

In the North it is also, amongst others, the responsibility of HIVOS to exchange the expertise present and available means with other organizations. To obtain this HIVOS will collaborate with congenial organisations like the International Humanist and Ethical Union (IHEU) and the International Lesbian and Gay Association (ILGA), especially where research is involved. Furthermore there will be collaboration with other organizations who are actively involved in the prevention of AIDS in the South, such as the Appropriate Health Resources and Technologies Group (AHRTAG), the UK NGO AIDS Consortium for the Third World, and the Women Global Network on Reproductive Rights (WGNRR).

The AIDS issue will also be part of the activities of HIVOS that are directed to the influencing of policies, both on national and international level. This will also generally take place in collaboration. To achieve this HIVOS participates in the AIDS Co-ordination Group (ACG), a group of Dutch NGOs who are actively involved in the AIDS problem of the developing countries. Apart from correlated information exchange, the ACG tries, for instance, to influence the DGIS- and EC policy in this field and to make funding corporations (like the WHO-Global Programme on AIDS and the EC-AIDS Task Force) more accessible to Dutch NGOs.

The AIDS problem in the South will be the theme of the next HIVOS campaign taking place in the period between January and May 1992, with a concentration of activities in the period from March, 30th until April, 10th 1992.

Humanistic Institute for Co-operation with Developing Countries (Hivos)

The Hague - The Netherlands, January 1992.

AIDS: IMPACT AND INTERVENTION - ORISSA: A CONSULTATION

2 - 3 August 1994 at Puri, Orissa

PROGRAMME:

2nd August

0930 - 0945	Welcome & Introduction Ben Witjes
0945 - 1045	Hivos Introduction and HIV/AIDS Policy Priorities Frans Mom Chair Sanghamitra
1045 - 1115	Coffee
1115 - 1215	HIV/AIDS Development Perspective Shyamala Nataraj Chair Lalitha Missal Discussion
1215 - 1300	Role of Counselling Peter Van Rooyen Chair Ben Witjes Discussion
1230 - 1400	Lunch
1400 - 1500	Coping with HIV/AIDS Panel Chair Rajendran Nathan Discussion
1500 - 1530	Coffee
1530 - 1630	HIV/AIDS - Community Responses, Ethics & Human Rights Vijay Thakur Chair Shobha Raghuram Discussion
1630 - 1700	Wild Fire - Workshop Game Vijay Takur

1800 - 2000	Films/Slides, etc.
2000	Dinner
3rd August	
0930 - 1030	Women - Reproductive Health, STDs & HIV Shyamala Nataraj Chair Bishka Banj Discussion
1030 - 1100	Coffee
1100 - 1200	HIV/AIDS - A Orissa Status Report Almas Ali Bisoi Chair N.M. Patti Discussion
1200 - 1300	Orissa NGOs Response Group discussion
1300 - 1430	Lunch
1430 - 1630	Plenary Shobha Raghuram Chair Frans Mom Group reports Discussion
1630 - 1700	Coffee
1700	Close
VENUE:	Hotel Holiday Resort Chakratirtha Road Puri 752002 Ph: 2440, 4370, 4371, 4372

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d (i) CHECK - LIST : COUNSELLING PEOPLE WITH HIGH RISK BEHAVIOUR*

PRE-TEST/PREVENTIVE COUNSELLING

1. Emphasise Confidentiality
2. Explore High Risk Behaviour
   A. Unsafe sex practices (consider spouse's behaviour)
   B. IV drug use (shared needles/sex with user)
   C. Blood/Blood products received
3. Explore HIV / AIDS Knowledge
   * explain HIV/AIDS
   * clarify misconceptions
4. Explore Test Implication: in relation to patient's life situation (e.g. : marriage, pregnancy etc.

<u>Clinical decision on whether to test</u>

If Test **Yes:** Proceed

Explain test: is for antibodies to HIV and <u>not an AIDS test</u>

* Meaning of negative result
* Meaning of positive result

5. Reason for Testing
   A. If negative - confirms lack of antibodies
   (Caution: window period-consider repeat test after 3 to 6 months)
   - removes uncertainty

   (Caution: does not mean immunity against HIV)
   B. If positive - know for sure
   - make adaptive change in life style
   - protect sexual partner
   - protect self - medical care
   - plan for future - financial ,legal ,emotions
   - explore expected reactions,
   available social supports

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* NACO Manual for HIV /AIDS Counselling- NACO, New Delhi, 1993. (Adapted from WHO Guidelines)

6. Who Should Know Result?
   - discuss implications/discrimination
   - partner notification/testing
7. Practicalities of Test - sample collection, getting result, give appointment
8. Assess Strategies for Coping
   * evaluate past handling of stressful situations
   * evaluate patient's social support network
9. Preventive Education
   * safe sex
   * proper use of condoms
   * clean needle use
   * reconsider life style
   * spread HIV/AIDS prevention message

POST-TEST: TEST NEGATIVE

1. Renew Relationship
2. Explain Negative Result
   - give time to absorb information
   - allow time to express feelings
3. Explain Lack of Immunity
4. Check Back to Confirm Understanding
5. Clarify Doubts/misconceptions
6. Evaluate Need for Retest
7. Address "Survivor" Reactions
8. Repeat Preventive Education
   - safe sex
   - proper use of condoms
   - clean needle use
   - reconsider life style
   - spread HIV/AIDS prevention message

POST - TEST: TEST POSITIVE

1. Renew Relationship
2. Follow Patient's Lead When to Disclose
3. State Result Clearly

4. Wait - give time to absorb information
   - give time for expression of feelings
   -listen
5. Integration of Result
   A. Intellectual
      explore understanding
      clarify misconceptions
   B. Emotional
      assess emotional impact
      validate reactions as normal
      give adequate time/follow up
   C. Behavioural
      assess commitment & understanding to risk reduction
      explore factors related to general health and
      immune functioning (stress nutrition, exercise, substance abuse, re-exposure to virus)
   D. Interpersonal
      * re-explore who to inform
      * impact on partner
      * how to break news (offer help & support)
      * plan to maximise support and minimise stress
   E. Medical
      * Plan health/early intervention. Avoid quacks
6. Arousing Hope; Advice and Empowerment
   * a realistically hopeful message without discounting concerns
   * focus on quality of life
   * empower participation in health issues
   * express your availability when needed
7. Plan for Future Course of Action:
   - focus on need for on going support
      * stress, anxiety, depression, anger
      * substance abuse
      * sexual & interpersonal issues
      * financial, occupational, legal, medical needs
   - resources ?
      * individual therapy

* support groups
* social network
* religious strengths

8. Provide Appropriate Brochures for Patients.

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d (ii) FREQUENTLY ASKED QUESTIONS ABOUT HIV/AIDS*

AIDS - the Acquired Immuno Deficiency Syndrome - is the late stage of infection caused by a virus, the Human Immunodeficiency Virus (HIV).

A person who is infected with HIV can look and feel healthy for up to ten years or more before signs of AIDS appear. But HIV steadily weakens the body's defence (immune) system until it can no longer fight off infections such as pneumonia, diarrhoea, tumours and other illnesses. All of which can be part of AIDS. Unable to fight back, most people die within three years of the first signs of AIDS appearing.

You probably know most of these basic facts about HIV and AIDS. But you may not be aware of some others that could be important to you.

1. How can one contract HIV?

AIDS is mainly a sexually transmitted disease. Most of all HIV infections have been transmitted through unprotected sexual intercourse with someone who is already infected with HIV. HIV can also be transmitted by infected blood or blood products (as in blood transfusions), by the sharing of contaminated needles, and from an infected woman to her baby before birth, during delivery, or through breast-feeding. HIV is not transmitted through normal, day-to-day contact.

2. Can I get AIDS from "casual contact" with an infected person?

No. This means that it is OK to play sports and work together, shake hands, hug friends or kiss them on the cheek or hands, sleep in the same room, breathe the same air, share drinking and eating utensils and towels, use the same showers or toilets, use the same washing water and swim in the same swimming pool. You cannot get infected through spitting, sneezing, coughing or through tears or sweat, or through bites from mosquitoes or other insects.

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* Information on HIV/AIDS is readily available on the internet.
The UNAIDS website //www.unaids.org has good links to other sites providing up-to-date information such as the Centres of Disease Control and Prevention, USA and the World Health Organisation.
For the Asian region:
The South East Asian Regional Office of the World Health Organisation, New Delhi has a web site called AIDS Watch - //www.who.ernet.in

3. How can I recognise if someone is infected with HIV?

There is no way of knowing whether someone is infected just by looking at them. A man or woman you meet at work, school, or a sports stadium; in a bar or on the street might be carrying HIV - but look completely healthy. But during this time of apparent health, he or she can infect someone else.

4. What should I do to protect myself from HIV?

There is no vaccine to protect people against getting infected with HIV. There is no cure for AIDS either. This means that the only certain way to avoid AIDS is to prevent getting infected with HIV in the first place.

5. What is safer sex?

You are safest of all if you do not have sexual intercourse. You are also safe if you are in a stable relationship where both you and your partner are free of HIV and neither of you has other sex partners. Sex without penetration is another way to have safer sex that greatly decreases your risk of getting infected with HIV. You can have a great deal of stimulation and pleasure through caressing, hugging, kissing, and massaging different parts of the body.

Safer sex also includes using a condom - but, using a condom correctly, and using one every time you have sex. Learn how to negotiate the use of condoms with your partner.

6. What can I do to convince my partner to use a condom?

Some people think that sex is not as enjoyable if you use condoms - perhaps you feel this way because of a bad or embarrassing experience, but that is not a good reason to risk your life or the life of your partner by not using them! Research has shown that when people use condoms the right way, and with confidence, there is little or no loss of stimulation or pleasure. For some people, it even lasts longer.

If you do not use condoms often, and if you still feel a bit awkward about using them, try practising a little by yourself. Just go out and get some condoms, read how to use them, practice using them, then use them every time you have sex.

7. Do you sometimes have sex without using a condom?

If you have had sex without a condom just one time, you have already put yourself in danger of infection with HIV. Maybe you have been lucky - maybe you have not yet been infected with HIV. You may not be so lucky next time. First of all, avoiding dangerous situations is the smarter way to go. Having casual sex is dangerous - but having casual sex without a condom is simply taking a needless and foolish chance of getting infected with HIV.

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d (iii) HIV TERMINOLOGY*

AIDS

AIDS - the abbreviation for the Acquired Immuno-Deficiency Syndrome - is a disabling and fatal disease caused by the human immunodeficiency virus (HIV). It is thought that everyone infected with HIV will eventually develop AIDS, because the body's immune system is steadily weakened by HIV. Unable to fight off infections, most people die within three years of the first signs of AIDS appearing.

Asymptomatic HIV Infection

The stage of HIV infection prior to the development of illness or clinical signs and symptoms.

Confidentiality

The protection of personal data and test results in order to ensure the rights and the welfare of the individual from whom such data are collected. Only the individual and the health professionals directly involved in the care of the individual are aware that certain tests were performed and can have access to test results. This information is not furnished under any circumstances to any other person without the individual's explicit consent. (See testing).

Counselling

Dialogue between a person in need and a care provider with the aim of reducing the stressful impact of HIV/AIDS on the individual and preventing transmission of HIV infection. Information, education and psychological support are given in a way which allows the individual to make decisions that facilitate preventive behaviours.

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The UNAIDS website //www.unaids.org has good links to other sites providing up-to-date information such as the Centres of Disease Control and Prevention, USA and the World Health Organisation.
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Discrimination

To make a distinction or to apply a measure which has a disproportionate impact or to give unfair treatment, on a categorical basis, for example, on the basis of a person's sex, sexual orientation, ethnicity, nationality, religion or any other such status, actual or assumed.

Epidemiology

The study of the incidence, distribution and determinants of an infection, disease or other health-related event in a population. Epidemiology can be thought of in terms of who, where, when, what, and why. That is, who has the infection/disease, where are they located geographically and in relation to each other, when is the infection/disease occurring, what is the cause, and why did it occur.

HIV

HIV (Human Immunodeficiency Virus) is the virus that causes AIDS. Two types of HIV are currently known: HIV-1 and HIV-2. World-wide, the predominant virus is HIV-1. Both types of virus are transmitted by sexual contact, through blood, and from mother to child, and they appear to cause clinically indistinguishable AIDS. However, HIV- 2 is less easily transmitted, and the period between initial infection and illness is longer in the case of HIV-2.

HIV Infection

Infection with the human immunodeficiency virus (HIV). HIV infection is primarily a sexually transmitted infection, passed on through unprotected penetrative sex. The virus can also be transmitted through blood transfusions, the use of un-sterilised injection equipment or cutting instruments and from an infected woman to her foetus or nursing infant. While some individuals experience mild HIV-related disease soon after initial infection, nearly all then remain well for years (see Asymptomatic HIV Infection). Then, as the virus gradually damages their immune system, they begin to develop illnesses of increasing severity, characterized by various combinations of symptoms and diseases, such as diarrhoea, fever, wasting, fungal infections, tuberculosis, pneumonia, lymphoma, failure to thrive and Kaposi's sarcoma.

HIV Sentinel Surveillance

The systematic collection and testing of blood from selected populations at specific sites, for

example, pregnant women attending ante-natal clinics, for the purpose of identifying trends in HIV prevalence over time and place. This is carried out according to a procedure called unlinked anonymous testing. (See Prevalence and Testing).

Immunodeficiency

The inability of the immune system to satisfactorily protect the body, which results in an increased susceptibility to various cancers and opportunistic infections.

Incidence

The frequency of new infections during a designated time period expressed as a proportion of the population at risk of the infection, disease or other health-related event.

Incubation Period

The time interval between infection and

seroconversion,
the onset of the clinical signs or symptoms of HIV-related disease or
the onset of AIDS. The term should always be used with reference to one of the specific events.

Infectiousness

The relative ease with which a disease is transmitted. The degree of infectiousness of HIV varies over the course of the incubation period, and is probably highest when people are first infected (prior to development of antibodies) and when they are symptomatic.

Intervention

A set of activities through which a strategy is implemented. For example, promoting safer sexual behaviours is one intervention to reduce sexual transmission of HIV.

Intravenous

Within a vein or veins. It is the introduction of a solution into a vein, usually through a needle.

Invasive

Used to describe any practice which involves the insertion of an object or instrument into the body. An example is tattooing (during which intact skin is pierced). In medicine, an invasive procedure is any procedure which involves the placing of an instrument into the body cavities or which requires the piercing or puncturing of intact skin.

Low-risk Blood Donor

A person who is at low or little risk of carrying infectious agents in his/her blood -usually people who donate their blood of their own free will and receive no payment for it, either in the form of cash or in-kind which could be considered a substitute for money.

Opportunistic Infections

Infections that are caused by microorganisms which the body's immune system is normally able to fight off. When the immune system is weakened or destroyed, as in HIV infection, opportunistic infections can then take hold. For example, oral thrush is caused by a fungus which is normally found in the mouth but which does not usually cause infection in people with a healthy immune system.

Palliative Care

Affording relief of symptoms but not a cure for AIDS.

Perinatal

Pertaining to or occurring during the periods before, during or shortly after the time of birth; that is, before delivery from the 28th week of gestation through to the first 7 days after delivery. The transmission of HIV from an infected woman to her foetus or new born child is referred to as perinatal transmission.

Person Living With HIV

An individual infected with HIV; also called a person who is HIV positive or a person who is HIV seropositive. As soon as an individual becomes infected, he or she is capable of infecting

others through sex, blood and perinatally. HIV infection is lifelong.

Prevalence

The proportion of a defined population with the infection, disease or other health related event of interest at a given point or period in time. Point prevalence is the proportion of a population with a disease at a specified point in time. Period prevalence is the total proportion of a population known to have had the disease at any time during a specified period.

Preventive Measures

Measures aimed at stopping the sexual, blood borne and perinatal transmission of HIV. For example, preventive measures aimed at decreasing sexual transmission include:
education to encourage people to avoid high-risk sex
prevention and treatment of other sexually transmitted infections
measures to make the environment, or overall situation, more supportive of safer sex, for example, a policy decision that condoms should be provided free in all hotel rooms.

Prostitute

A prostitute is an individual who engages in direct sexual activity with another person in exchange for money, goods and/or drugs. The term includes those who earn money through sexual labour on a regular basis, as well as those who do it casually or informally, or on an intermittent basis. Prostitutes can be male, female or cross-gender (for example, transsexuals, transvestites); they can be adults, adolescents or, sometimes, children (See Sex work and Sex worker).

Risk Factors

Conditions or behaviours which make it more likely that a person will become infected with HIV. These factors might include:

- involvement in any sexual relationship other than one which has been mutually exclusive and HIV-negative for a sustained period of time;
- presence of STD;
- injecting drug use;
- history of blood transfusions; skin-piercing; invasive, surgical or dental procedures that

were done under possibly un-sterile conditions or with contaminated blood or blood products;
- sexual intercourse with a partner who has any of these risks listed.

Safer Sex

Any sexual practice that aims to reduce the risk of passing HIV from one person to another is safer sex. Examples are non-penetrative sex, or vaginal intercourse with a condom. During unsafe sex, on the other hand, fluids that can transmit HIV (semen, vaginal fluid or blood) may be introduced into the body of the sex partner. There are five elements of safer sex: consistent condom use; reducing the number of partners; practising mutual fidelity; engaging in safer sexual acts, including delaying the age at first intercourse; or abstaining from sex.

Screening

The systematic laboratory testing of donated blood, blood products, tissue (including sperm) and organs for the purpose of preventing HIV transmission to a recipient. (See testing).

Sensitivity (of HIV test)

A measure of the responsiveness of a test to the presence of HIV infection. An HIV antibody test with high sensitivity will have few falsely negative results because it will detect even very low levels of antibody, but it may also identify some people as being positive for HIV antibody when in fact they are not (falsely positive). (See specificity).

Serological Test

Any of a number of laboratory tests that are performed on the clear, liquid portion of blood (serum).

Seroprevalence (HIV, STD)

The percentage of a population from whom blood has been collected that is found, on the basis of serology, to be positive for HIV or other STD agents at any given time.

Sex Work

A broader term than "prostitution", taken to mean the trade of sexual acts or services for money or goods on a formal, regular and professional basis or an informal, intermittent and casual basis. Sex work is often part of "entertainment", "hospitality", "massage", "escort services". Employment in sex work includes owners, managers and organizers of sex work establishments.

Sex Worker

A person who trades sexual acts or services for money or goods.

Sexually Transmitted Disease (STD)

A disease or infection which is usually transmitted by sexual contact (for example, Neisseria gonorrhoea) or where sexual contact is a significant mode of transmission (for example, hepatitis B).

Social Marketing

Application of private sector marketing techniques to the sale of products, such as condoms, that fulfil a social objective. Marketing refers to having the right product at an accessible place at an affordable price with appropriate promotion to one or more targeted audiences.

Specificity (of HIV test)

The accuracy with which a test can detect the presence of a particular substance, such as antibodies to a particular organism. A test with high specificity will have few false positive results. (See sensitivity)

STD Care (Case Management)

Overall provision of care for a person seeking medical treatment for STD, including diagnosis and treatment, health education for prevention of future infection, provision of condoms and recommendation of partner notification.

Stigmatise

To regard or treat people as shameful, disgraceful or discredited because of a difference (real or imagined) from perceived social "norms". People with HIV infection or AIDS, or those close to them, are often stigmatised on the basis of pre-existing prejudices or on "moral" grounds not necessarily related to the infection itself. For example, a man with AIDS may be stigmatised because of a pre-existing prejudice or moral value with respect to homosexuality.

Testing (for HIV)

1. The testing may be used in order to screen blood for transfusion or organs or tissue for transplantation (see screening), or in order to test an individual.
2. The testing of individuals is generally used to determine their HIV infection status. All testing in this sense can be categorised along three axes:

    a. client-initiated, health provider-initiated, or initiated or required by a third party for other than health purposes;
    b. with or without informed consent; and
    c. anonymous, confidential or non-confidential. These terms are defined below.

Client-initiated testing: HIV testing requested by a client on his/her own initiative.

Health care provider-initiated testing: Testing offered by the health care worker.

Testing initiated or required by a third party for other than health reasons: HIV testing for other purposes, such as immigration, employment or insurance.

Testing with informed consent: HIV testing performed only after the client has given informed consent to it. "Informed" in this context means that in discussion (pre-test counselling) the client has been told and understands the risks and benefits of testing, as well as of alternatives to such testing. "Consent" means the giving of express agreement to HIV testing in a situation free of coercion, in which the client should feel equally free to grant or withhold consent.

Testing without informed consent: HIV testing in which informed consent, as defined above, has not been requested and given.

Routine testing: Is sometimes used to mean the HIV testing of individuals without their

knowledge, unless they specifically refuse such testing. Examples are routine testing applied by hospitals to patients, and sometimes to people attending antenatal or STD clinics.

Mandatory testing: HIV testing without informed consent which the individual is compelled to undergo. The term refers both to situations in which the individual clearly has no alternative, as when prisoners are tested involuntarily, and to situations in which refusal of testing is not realistic or would cause the individual undue hardship, as when HIV testing is required prior to employment or marriage.

Anonymous testing: HIV testing in which the blood sample and test result are identified only by code, not by name, with no personal identifiers to link the sample to the person whose blood is to be tested.

Linked anonymous testing: HIV testing in which blood sample and test result are identified only by code, not by name, with no personal identifiers to link the sample to the person whose blood is to be tested. The code is known only to the client.

Unlinked anonymous testing: HIV testing after prior removal of all personal identifiers, so that there is no way that the blood can be traced to its source.

Confidential testing: HIV testing in which only the client and the health professionals involved in the client's direct care know that the test was performed and have access to the test results. This information is not furnished under any circumstances to other health providers, health authorities, employers, insurers, schools or other third parties without the patient's explicit consent.

Non-confidential testing: HIV testing conducted neither anonymously nor confidentially.

Voluntary testing: Anonymous or confidential testing initiated by either the client or his/her health provider and performed with the client's informed consent.

Supplemental HIV testing: The testing of a sample for a second time using a different test format having equal or greater specificity, in order to validate an initial positive result for HIV antibody. Such supplemental testing can be carried out either by repeating the initial test, using a different format, or by using another testing procedure (see Specificity).

Transfusion

The introduction of whole blood or blood components directly into the blood stream, usually into a vein.

Virus

One of a group of minute infectious agents not visible using an ordinary light microscope. They are characterised by a lack of independent metabolism and by the ability to replicate only within living host cells. Viruses contain DNA or RNA, but not both. Viruses are customarily separated into three sub-groups on the basis of host specificity, namely bacterial viruses, animal viruses and plant viruses.

Window Period

The time interval between infection with HIV and the appearance of detectable antibody to HIV in the blood.

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d (iv) HOW TO USE THE RIGHT CONDOM THE RIGHT WAY*

First, pick the right condoms.

- The best ones to use are made of latex rubber. These are less likely to break or leak than animal-skin condoms or the thinner "more sensitive" condoms.
- If you have a choice, pick condoms with lubrication (slippery liquid or gel) already on them. This makes them less likely to tear during handling or use. Never use an oil-based lubricant like Vaseline with a condom.
- Some condoms come packaged with a spermicide (such as nonoxonyl-9), a chemical designed to kill the sperms. Most spermicides also kill viruses. Although they are not available everywhere, condoms that include a spermicide may provide an additional barrier against the AIDS virus.
- New condoms are stronger than old ones. If you keep a condom for too long, the rubber loses its strength. Store them in a cool, dry place out of direct sunlight. Heat quickly damages rubber, so do not store condoms in hot spots such as the glove compartment of a car. Many condom packages will have either a manufacturing date or an expiration date on them. This is helpful since it provides an indication of age. Older condoms are likely to be weaker, and should be through out. A condom should also be thrown out if it feels hard, dried out or very sticky, or if it looks discoloured or was in a torn or damaged package - so take a look at them as you use them.
- Condoms should never be re-used - use a new condom each time you have sex. So, keep a supply of condoms on hand. Carry some condoms with you whenever you go out. Even if you do not use them, you can share them with friends who may have forgotten theirs.

Next, using condoms should be discussed with the person you are planning to have sex with.

- Waiting to pull out a condom until the moment before you have sex is the worst possible time to bring up the subject. Your partner may get angry that you have waited so long and may feel tricked, or not trusted.
- The best time to introduce the subject of using condoms is the first time you think about

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having sex with someone. Planning to protect yourself and your partner from getting a sexually transmitted disease, especially AIDS, shows that you care about your health and about your partner's health. It also shows that you are aware of the risks of unprotected sex at a time when AIDS is a serious epidemic all over the world.

- The person you are thinking about having sex with may not agree at first when you say that you want to use a condom when you have sex. You may need to offer some arguments about why you feel that way, using facts about safer sex. If the person still resists, then the smart thing to do is not to have sex. If that person cares so little about his/her health - or yours - then you should find someone else who does care.

Once you and your partner are comfortable with the idea of using a condom and are ready to have sex, here is how to use a condom the right way:

- Only open the package containing the condom when you are ready to use it. Otherwise, the condom will dry out. Be careful not to tear or damage the condom when you open the package. If it does get torn, throw it away and open a new package.
- Condoms come rolled up into a flat circle. They can only be unrolled onto an erect ("hard") penis.
- Before the penis touches the other person, place the rolled-up condom, right side up, on the end of the penis.
- Hold the tip of the condom between your thumb and first finger to squeeze the air out of the tip. This leaves room for the semen to collect after ejaculation.
- Keep holding the top of the condom with one hand. With the other hand (or your partner's hand), unroll the condom all the way down the length of the erect penis to the pubic hair. If the man is uncircumcised, he should first pull back the foreskin before unrolling the condom.
- Always put the condom on before entering the partner.
- If the condom is not lubricated enough for you, you may choose to add a "water-based" lubricant, such as silicone, glycerine, or K-Y jelly. Even saliva works well for this. Lubricants made from oil (cooking oil or shortening, mineral or baby oil, petroleum jellies such as Vaseline, most lotions) should never be used because they can damage the condom.
- If you feel the condom slipping off during sex, hold it at the base to keep it in place during the rest of this sexual act. It would be safest for the man to pull his penis out and put on a new condom, following all the steps again.

After sex, you need to take the condom off the right way.

- Right after the man ejaculates ("cums"), while still inside his partner, he must hold onto the condom at the base, near the pubic hair, to be sure the condom does not slip off.
- Now, the man must pull out while the penis is still erect. If you wait too long, the penis will get smaller in size, and the ejaculate ("cum") will spill out of the condom.
- When the penis is completely out, take off the condom and throw it away.
- If you are going to have sex again, use a new condom and start the whole process over again!

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Hivos Regional Office Bangalore:

List of available Hivos publications

1. Hivos Regional Office ***Annual Reports*** 1992, 1993,1994, 1995, 1996.

2. Technical Report Series 1.1, ***AIDS: Impact and Intervention***,
   Editors: Rajendran Nathan, Joy D'Souza and Shobha Raghuram, 1992.

3. Technical Report Series 1.2, ***Development Policies:Issues and Challenges for the '90s***,
   Editor: Shobha Raghuram, 1992.

4. A Reference Manual, ***Management and Accounting Systems in the Voluntary Sector,***
   Editor: Sangeetha, 1992.

5. Technical Report Series 1.3, ***Future of the Co-operatives in India***,
   Editor: Reena Fernandes, 1993.

6. Proceedings of a Consultation Gender and Development ***Women in India: Reflecting on our History Shaping our Future,***
   Editor: Jamuna Ramakrishna, 1993.

7. ***Savings and Credit Systems of the Poor: Some Non - Governmental Organisation (NGO) Experiences***, A Hivos-Novib Publication
   Editor: D. Rajasekhar, 1994.

8. ***Structural Adjustment: Economy, Environment and Social Security,***
   Editors: Shobha Raghuram, Heiko Sievers and Vinod Vyasulu, Macmillan, New Delhi, 1995.

9. Technical Report Series 1.4, ***Rethinking Population***, Jointly organized by Hivos Regional Office South Asia, Bangalore, Co-ordination Unit, Bangalore and the Center for Reproductive Law and Policy, New York,
   Editors: Shobha Raghuram and Anika Rahman, 1996.

10. Leela Gulati and R Ramalingam, ***Poverty and Deprivation: Some Inter-State Comparisons,***
    A Hivos Monograph, 1996

11. J. Mohan Rao, ***Local Development in a Globalizing World,***
    A Hivos Monograph, 1996

12. Technical Report Series 1.5, ***Voluntary Organizations and Good Governance: Formation, Resource Mobilisation, Accounting and Management,***
Editor: Sangeetha, 1997.

13. Technical Report Series 1.6, "***Recasting HIV/AIDS as a Development Issue: Of Rights and Resistance", 1997.***
Editors: Shobha Raghuram and Rajendran Nathan

Forthcoming Publications:

14. Technical Report Series 1.7, ***Livelihood Strategies of the Rural Poor and the Environment Challenges Ahead,***
A Joint initiative of Hivos and AME, 1997.
Editor: Jamuna Ramakrishna

15. Leela Gulati and R. Ramalingam, ***Poverty and Deprivation: Profiles of Madhya Pradesh and Bihar***. A Hivos Monograph 1998

These publications are for internal circulation.

The Editor

Hivos

Hivos, the Humanist Institute for Co-operation with Developing Countries, is a development agency established in 1968 by representatives of the Humanist movement in The Netherlands. Hivos is inspired by the humanist, secular outlook. Hivos co-operates with Non-Governmental Organisations (NGOs) and social organisations in the South. It supports organisations that enable marginalised people to assert their rights and improve their access to decision-making.

In its policy Hivos gives priority to the following five special themes: economic self-reliance, culture and the arts, gender, women in development, environment and development, human rights and HIV/AIDS. For the first two sectors separate funds have been set up, viz., the Hivos Triodos Fund and the Hivos Culture Fund.

In order to have an impact, Hivos wishes to focus its funding efforts. One way in which this is done is by limiting the geographic area in which Hivos works. In 1996, Hivos provided support to 679 organisations in 29 countries concentrated in Southern and East Africa, Central America, the Andes, and Asia. In Asia, Hivos concentrates its efforts in India, Sri Lanka, Indonesia, Malaysia and the Central Asian Republics of the former Soviet Union. India is the largest country programme in Asia. Hivos supports organisations in the following states: Tamil Nadu, Karnataka, Andhra Pradesh, Orissa, Gujarat, Goa, Maharashtra, Rajasthan and New Delhi.

As one of the four Dutch co-financing agencies, Hivos receives a large part of its funds from the co-financing budget line of the Ministry for Development Co-operation. Hivos's total expenditures for 1996 amounted to Df.70.2 million guilders, of which Dfl.56.3 m, consisted of co-financing funds. Other funding sources were the European Union, Dfl.2.3 m, the additional project-based funding from the Dutch government, Dfl.9.0 m. and private donations, Dfl.2.6 m. The value of the loans portfolio of Hivos and the Hivos Triodos Fund amounted to Dfl.12.5 m guilders on 31 December, 1996.

HIVOS

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